Barriers and enablers to childhood cataract services in India

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Finally, I dedicate this thesis to my parents, other family members and friends who supported me whole heartedly to pursue my dreams.

DECLARATION

I, Sheeladevi Sethu, confirm that the work presented in this thesis is my own.

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ABSTRACT

There is little epidemiological information about cataract in children globally and thus a lack of evidence to guide policy related to childhood cataract. Early presentation for cataract surgery in children is an important first step for effective treatment.

The overall aim of this research was to determine the age at childhood cataract surgery in India and to understand the barriers and enablers to accessing childhood cataract services in the region. A mixed methods approach was used. Quantitative data were obtained via a questionnaire in nine different eye hospitals in eight states in India. Qualitative data were collected from the perspectives of parents and carers and primary eye care providers using in-depth interviews and focus group discussions respectively and Theoretical Domains Framework (TDF) of behaviour change was used for analysis.

A systematic review was conducted to estimate global prevalence of childhood cataract. This was estimated to be 1.14 /10000 overall, and 0.46 /10000 in low and lower middle-income economies. The mean age at surgery for congenital cataract in India was 4 years and for developmental cataract it was 8 years, but these numbers varied significantly between the regions in the country. Delays to surgery occurred at recognition, when accessing the hospital and delayed surgery at the hospital.

The barriers and enablers identified from the perspectives of the parents and carers suggest a need for behavioural change intervention to enhance health seeking behaviour in the communities. The findings suggest gaps in knowledge and awareness among the primary care team which should be further investigated and addressed.

Based on these research findings several recommendations were identified and a preliminary recommended intervention strategy was developed to achieve behaviour changes with the aim of increasing early uptake of childhood cataract services in India.

Chapter 1

1 Introduction and research overview

1.1 Epidemiology of Childhood blindness

Childhood blindness occurs due to a group of diseases and conditions occurring in childhood or early adolescence, which, if left untreated, result in blindness or severe visual impairment. According to Article 1 of UNCRC[1] (United Nations Convention on the Rights of the Child), “A child means every human being below the age of 18 years unless, under the law applicable to the child, majority is attained earlier”. The World Health Organisation defines Blindness as a corrected visual acuity worse than 3/60 in the better eye and severe visual impairment as a corrected visual acuity in the better eye <6/60-3/60.

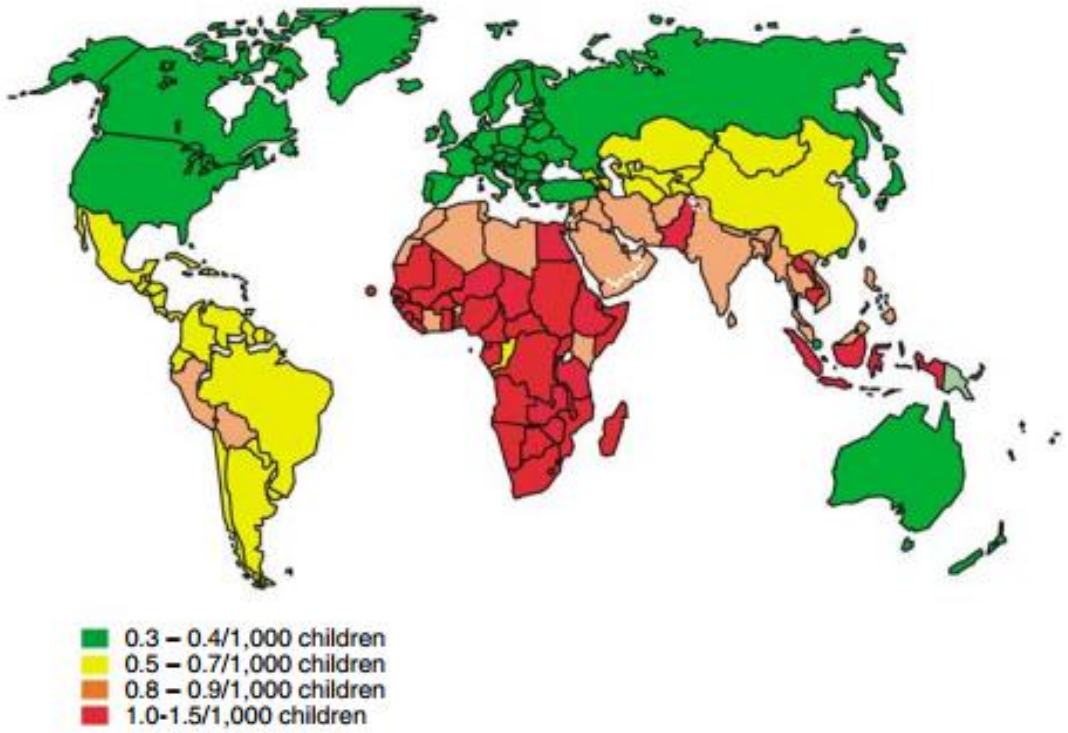
Prevalence of blindness in children varies widely from region to region and it is mainly associated with the socioeconomic development and under-5 mortality rates (Gilbert and Foster, 2001b). In low-income countries with high under-5 mortality rates, the prevalence may be as high as 1.5 per 1000 children, while in high-income countries with low under-5 mortality rates, the prevalence is around 0.3 per 1000 children, see Figure 1.1 for estimated prevalence of blindness in children in different countries (Gilbert, 2007).

Worldwide, around 1.4 million children are blind (Solebo et al., 2017); 1 million of these children live in Asia and 300 000 in Africa (WHO, 2000). About 40% of the estimated 1.4 million cases of blindness in children below the age of 15 years could have been avoided. (Muhit et al., 2007a). India alone is home to over 270,000 blind children (Gilbert, 2003). It is estimated that 500,000 children become blind each year globally, and 50-60% of these

[1] UNCRC (United Nation’s Convention on the Rights of the Child),adopted by the UN General Assembly in 1990, is the widely accepted UN instrument ratified by most of the developed as well as developing countries, including India. The convention provides standards to be adhered to by all State Parties in securing the best interest of the child and outlines the fundamental rights of children

children die within one or two years primarily due to underlying conditions causing blindness (e.g. Vitamin A deficiency, measles, congenital rubella).

Figure 1.1 Estimates of the prevalence of blindness in children, using under 5 mortality rates as a proxy indicator (Gilbert, 2007)



There is limited data on blindness among children of developing countries. Available data are estimates mainly based on extrapolations from surveys of children in schools for the blind (Dandona et al., 1998b). There is little information from population-based surveys, disease-specific surveys or community based rehabilitation (CBR) programs. Registers of the blind and birth cohort studies are not usual in developing countries. Based on available data, the estimated prevalence of childhood blindness in India is five times more compared to the higher income countries (Dandona, 2001).

There is little data on the incidence of blindness among children worldwide. Data obtained from registers of the blind in Nordic countries suggest an incidence of 6-11/100,000 children per year (Riise, 1993). There are an estimated 500,000 blind children becoming blind each year, and the majority of these children are estimated to die within one or two years primarily due to underlying conditions causing blindness, such as Vitamin A deficiency, measles and congenital rubella(Gilbert CE, 1998).

Although the estimated prevalence of blindness among children is about 10 times lower than that among adults, childhood blindness remains a high priority under VISION 2020: The Right to Sight because it is estimated that the cumulative number of blind-person-years worldwide due to childhood blindness ranks second only after the cumulative number of blind-person-years due to cataract blindness (Gudlavalleti, 2017). Childhood blindness alone accounts for 28.7% of the economic burden of blindness in India (Shamanna et al., 1998). The cumulative economic loss from childhood blindness, calculated for the lifetime of 0.25 million blind children in India assumed to have lost 33 working years of their life, amounts to US$ 22.2 billion (Thomas et al., 2005).

1.2 Causes of blindness in children

There is a marked variation in the major causes of blindness among children in different parts of the world. This variation is largely affected by socioeconomic development, and the availability of primary health care and eye care services. Further, variation also occurs within the country in both rural and urban settings that reflects the regional balance of the determinants of specific diseases (Solebo and Rahi, 2014).

In Europe and North America, genetic factors are responsible for between 30-50% of cases, e.g. familial congenital cataract and hereditary retinal diseases (Foster, 1988), whereas in Africa and in Asia, nutritional factors and ocular infections account for more than half of all childhood blindness (Foster and Sommer, 1986). Retinopathy of prematurity is an important cause in middle-income countries. Other significant causes in all countries are congenital abnormalities, such as cataract, glaucoma, and hereditary retinal dystrophies. There is emerging evidence that cataract is becoming an increasingly important cause in Africa (Bowman, 2005). A study from India showed that 50% of children surveyed in the schools for the blind suffered from potentially preventable and or treatable conditions with cataract being one of the leading causes (Titiyal et al., 2003).

The causes of blindness can be classified using a descriptive anatomical classification that depends on the site in the eye most affected or an etiological classification based on the time of onset of the insult leading to blindness. The anatomical classification is useful to collect information on all children while the etiological classification is more useful for planning preventive measures (WHO, 1999.).

1.3 Avoidable causes of blindness in children

About one-third of the causes of childhood blindness are avoidable either through prevention or through early treatment, so an understanding of the causes and treatments is a priority.

Avoidable causes of blindness in children

Preventable conditions	Treatable conditions
Corneal Scarring due to: vitamin A deficiency measles infection ophthalmia neonatorum harmful traditional practices infective corneal ulcers	Cataract Glaucoma Retinopathy of prematurity Uveitis Corneal diseases (corneal ulcers and opacity)
Intrauterine factors rubella toxoplasmosis other teratogens such as alcohol	
Perinatal factors: retinopathy of prematurity (ROP) birth hypoxia	
Hereditary diseases risk counselling for dominant diseases	

With significant reductions in some of the preventable causes of blindness such as measles and vitamin A deficiency, cataract is becoming the major cause of treatable blindness in children in developing countries (Waddell, 1998).

1.4 Childhood Cataract

Cataract, which is an opacity of the crystalline lens, is an important problem in children worldwide. It affects one or both eyes and the bilateral cataract is more common than unilateral. During infancy, a cataract not only blurs the retinal image but also disrupts the development of the visual pathways in the central nervous system (Wilson ME, 2005). Because of visual deprivation with both unilateral and bilateral cataracts, successful management requires early detection and referral for treatment. Early diagnosis and treatment are of crucial importance to prevent the development of irreversible stimulus-deprivation amblyopia (Medsinge and Nischal, 2015). Amblyopia is a disorder of reduced visual function from abnormal visual experience caused by strabismus, anisometropia, or visual form deprivation during the critical period of visual development (Chua and Mitchell, 2004).

Cataracts are defined by the age at onset: a congenital or infantile cataract presents within the first year of life, whereas cataract which presents after the first year but within the first decade of life is known as developmental or juvenile cataract (Hejtmancik, 2008). However, it is very unlikely to determine the age at onset unless the children are screened every day which makes it impossible to determine accurately the age at which the cataract presents. Hence, previous studies on childhood cataract have adopted a logistically convenient definition to define it. For example, these three studies (Mwende et al., 2005, You et al., 2011, Medsinge and Nischal, 2015) categorised cataract as congenital if it was recognised by the child's carers or presented at the hospital when the child was below the age of one year. All cases recognised after 12 months were defined as developmental cataract, unless caused by trauma (and categorised as traumatic cataract). Though this definition is used in the literature, it is flawed. For example, the cataract may be congenital but the carers may not recognise it within one year or they may not bring the child to the hospital within one year. Such cases may be wrongly categorised as developmental cataract. A major review on infantile cataracts by Lambert et al (Lambert and Drack, 1996) defined all cataracts developing during the first 18 months of life as infantile cataract since it was difficult to establish the age of onset with certainty. In such situations, morphology of the cataract gives some clues in determining the age of onset and this is described later in morphology section. In addition to categorisation as part of research, clinicians follows certain clinical criteria to define cataract in children.

1.4.1 Anatomy of the lens

The crystalline lens plays a vital role in the vision of vertebrates by facilitating variable fine focusing of light onto the retina (Majeed et al., 2008). The crystalline lens has two principal optical properties: transparency and refractive power. The lens has an equatorial diameter of 6.5 mm at birth and a maximum anteroposterior thickness of 3.5 mm and by early adulthood the lens has a stable equatorial diameter of approximately 9 mm and an anteroposterior depth of 5 mm (Creig, 2013). The lens is comprised of a very high concentration of protein (approximately 300 mg/ml), that is necessary for the refractile properties of the tissue. Due to this very high protein concentration, the new-born human lens is completely transparent. During aging, the lens slowly loses some of its transparency. In the small percentage of patients with congenital cataract, opacification occurs at a much younger age, due to genetic mutation (Takemoto and Sorensen, 2008).

The lens and cornea function together to transmit and refract light. While the cornea has additional protective functions, the main functions of the lens are to transmit light and focus it on the retina. In mammals the lens is the only tissue capable of accurately focusing light onto the retina, in a process called accommodation (Hejtmancik, 2008). The human lens is colourless when young, and a gradual increase in yellow pigmentation occurs with age, resulting in some decrease in perception of blue light (Lerman, 1980).

1.4.2 Morphology

Understanding the embryology of the lens can be helpful in classifying infantile cataracts. The lens forms from surface ectodermal cells by the beginning on the 28th day of gestation and on the 45th day of gestation the primary lens fibres are formed.

Infantile cataracts are usually subdivided on the basis of their morphology (Lambert and Drack, 1996) (Table 1.1). The morphology of the cataracts offers important clues to their age of onset and visual prognosis. In addition, it provides insights into the aetiology of a cataract. When possible, a slit lamp examination is invaluable in identifying the morphology. Refinements in the knowledge of morphology can be obtained intraoperatively (Wilson et al., 2011). The morphology is largely determined by the anatomy of the lens, its embryology, and the timing and nature of the insult that caused it.

Table 1.1 Morphological classification of infantile cataract

Major types of infantile cataract	Sub groups	Characteristics
Zonular – the most common type	Nuclear	• Opacification of a central zone of the lens. • They are bilateral in two thirds of affected patients and are commonly associated with microphthalmos and micro cornea.
	Lamellar	• Lamella of lenticular opacification sandwiched between a clear nucleus and cortex. • They are usually bilateral, but frequently an inter ocular difference in the degree of lenticular opacification leads to amblyopia.

	Sutural	• opacities of the lens sutures • Often first noted as an incidental finding during a routine ocular examination.
	Capsular	• opacities which involve either the anterior or posterior lens capsule, sparing the lens cortex • Anterior capsular opacities are usually visually insignificant
Polar- opacities of the sub capsular cortex in the polar regions of the lens	Anterior	• Visually insignificant and ninety percent of are unilateral. • When bilateral, they are commonly asymmetrical which needs to close follow-up for the amblyopia risk. • They are readily visible without special instrumentation, they are frequently diagnosed soon after birth by a parent or primary care physician.
	Posterior	• Usually small and diagnosed without ophthalmoscopy or bio microscopy. • Causes vision impaired due to its close proximity to the macula • Commonly present in children with aniridia.
Total cataract		• In some cases they can be observed to form from partial cataracts, while in other cases the lens is completely opacified when the cataract is first diagnosed.
Membranous		• Form when the lens cortex and nucleus are partially or completely reabsorbed, leaving behind a small amount of opacified lens material sandwiched between the anterior and posterior lens capsules. • They are associated with syndromes e.g. congenital rubella syndrome.

Some morphological types of cataracts have a better prognosis than others. Anterior polar, lamellar, and sutural cataracts are associated with the best visual prognoses, whereas

dense, central, and posterior cataracts have poorer visual prognoses (Amaya et al., 2003). Developmental cataracts generally have a more favourable visual prognosis than congenital cataracts.

1.4.3 Visual development in childhood

Visual acuity improves rapidly in the first 6 months after birth and more gradually thereafter, and reaches adult values at 4–6 years of age (Magnusson et al., 2002). In the case of congenital bilateral cataracts, visual deprivation in early infancy disturbs the normal visual acuity development in children. Visual experience is necessary for the development of neural networks and normal function. During a so-called critical period in early infancy (Birch and Stager, 1996) and a later period of neural plasticity until the age of 8 years, the visual system is susceptible to abnormal visual stimulation and is amenable to treatment (the latter being possible to some extent even in adult life (Hooks and Chen, 2007). Any disorder during this early critical period results in abnormal visual development, a form of developmental cerebral visual impairment called as amblyopia.

Unilateral cataract causes stimulus deprivation amblyopia, which continues until the cataract is removed and appropriate optical correction is provided. However, even after the optical correction, the affected eye may continue to have differential vision. If the insult to the visual system is occurred early in life, the amblyopia occurred due to this is considered very severe and resistant to treatment (Antonio-Santos et al., 2014a). Amblyopia is treatable within the period of plasticity, but beyond this period treatment is much less likely and amblyopia is associated with permanent impairment (Solebo and Rahi, 2014).

Childhood Cataract is an avoidable cause of blindness worldwide, see table 1.1 and is a priority for the VISION 2020: The Right to Sight Initiative (Thylefors, 1998a). Though it is a rare disease, childhood cataract is one of the most important causes of blindness and severe visual impairment in children and is responsible for 5% to 20% of paediatric blindness worldwide (Gilbert, 2007) (see Table 1.2). It is estimated that there are 200 000 children worldwide blind from cataract and that a further 20 000 – 40 000 children are born each year with congenital cataract (Foster et al., 1997). Globally the incidence of cataract in childhood has been reported as 1 – 15/10 000 live births (Gilbert, 2003). Thus, childhood cataract is one of the major causes of blindness, for example, it has been estimated that

restoring the sight of one child blind from cataracts may be equivalent to restoring the sight of 10 elderly adults (Foster et al., 1997).

Table 1.2 Magnitude and pattern of cause of blindness in children (exact copy from Gilbert, 2007)

		Per 10 million total population				
Level of development	*% of population aged 0–15 years*	*No. of children (million)*	*Prevalence of blindness*	*Number of blind children*	*Major causes*	*Number affected*
High income	20	2	0.3/1000	600	Scar	0
					Cataract/glaucoma	60
					ROP	60
					Others[a] (mainly CNS)	480
Middle income	30	3	0.6/1000	1800	Scar	0
					Cataract/glaucoma	360
					ROP	450
					Others[a]	990
Low income	40	4	0.9/1000	3600	Scar	720
					Cataract/glaucoma	720
					ROP	0
					Others[a]	2160
Very low income	50	5	1.2/1000	6000	Scar	3000
					Cataract/glaucoma	900
					ROP	0
					Others[a]	2100

CNS, central nervous system; ROP, retinopathy of prematurity.
[a]Mostly unavoidable causes such as congenital anomalies, optic atrophy, cortical visual impairment, retinal dystrophies.

There is a paucity of epidemiological information on the burden of childhood cataract worldwide. Many studies were conducted in schools for the blind across the world to estimate the various causes of the blindness. Previous reports from West Africa, South India and Chile showed that lens abnormalities contributed to 15.5%, 7.4% and 9.2% of all blindness respectively in those regions (Gilbert et al., 1993). In Eastern Africa studies conducted in schools for the blind in Malawi, Kenya and Uganda found that 13.1%, 9.1% and 27.6% of children surveyed respectively had an unoperated cataract (Gilbert et al., 1995). In Ethiopia, unoperated cataract or aphakia accounted for 9.2% of blindness in schools for the blind (Kello and Gilbert, 2003).

Research in Malawi demonstrated that many blind children and those with low vision who might benefit from surgical intervention did not have an operation. Most parents did not know what was involved in surgery nor did they understand the cause of their child's blindness (Karin van Dijk, 2000).

Cataract blindness in children presents an enormous problem to developing countries in terms of human morbidity, economic loss, and social burden (Wilson et al., 2003). Childhood

cataract affects the quality of life (QOL) of the child and their parents and family. Recently, a team of researchers reported the need for specific health-related quality of life (HRQOL) and functional vision concerns of children with cataract and parents in developed country (Castaneda et al., 2016) to measure the impact.

Cataract in children may be congenital or acquired, unilateral or bilateral (Gralek et al., 2007) and in all cases is treatable provided that the treatment occurs in early childhood, and more details on the period of plasticity and amblyopia is discussed later under the importance of early treatment.

1.4.4 Causes of cataract in children

In about 50% of the children with bilateral cataract the causes can be established and in approximately half of the cases of congenital cataract, the cause is due to unknown aetiology (Harley and Hertzberg, 1965) and another one third are believed to be genetically based. The causes vary between geographical regions. The most common aetiology in developed countries in Europe and the United States (US) are autosomal dominantly inherited cataracts (Beigi et al., 1993). In the developed world, the cause of bilateral congenital cataracts is, in most cases, idiopathic. About one third of the cases are hereditary, without a systematic disease.

Several intrauterine infections such as toxoplasmosis, rubella, cytomegalic inclusion disease, herpes infection, varicella and syphilis can cause congenital cataract (McCarthy et al., 1980). Of these, rubella is the most important. Rubella cataract is usually bilateral but may be unilateral.

Congenital rubella syndrome (CRS) is a cause of cataracts related to low rubella immunization rates (Lambert, 2007). When the woman infected with rubella virus during the first part of pregnancy, there is a high risk to develop CRS. CRS is a cause of preventable morbidity including childhood blindness and deafness and recognising its effects, the World Health Organization (WHO) has advocated the use of rubella containing vaccines (RCV) in many countries. 52% of the developing countries, including India, which account for two-third of the global birth cohort, are yet to implement it in their national schedule. Though India has a policy of Measles Mumps and Rubella (MMR) vaccination, the coverage of this vaccine is quite low which leaves many adolescent girls and women at the child bearing age with risk of rubella infection during pregnancy (Singh, 2014).

With an increase in the number of premature children and the resultant increase in retinopathy of prematurity (ROP), this has been recognised as another important avoidable cause of blindness in children. Cataracts in these infants may occur spontaneously or may be related to the interventions undertaken to treat the underlying retinal pathology, such as laser or vitreous surgery. Hence, ROP treatment can invariably cause cataract in children irrespective of the type of treatment they undergo (Ezisi et al., 2016).

Consanguinity has been reported as an important factor in the development of autosomal recessive diseases and congenital anomalies including congenital cataract is also associated with it. Consanguineous marriages are common among certain communities in India (Hornby et al., 2001). Cataract can be caused by blunt or perforating trauma to the eye ball and this may occur at any stage of life.

1.5 Cataract surgery in children

Cataract surgery in children has improved significantly in recent decades. This is mainly as a result of improved screening, modern surgical techniques and improved intraocular lenses implantation.

However, the visual outcome post cataract surgery depend on a number of factors, including;

1. The age of onset of the cataracts
2. The age at which surgery is performed
3. Associated ocular and systemic conditions
4. Compliance with optical and occlusion therapy following surgery.

Congenital cataracts that affect the child's vision need to be treated with cataract removal surgery. The best period for treating the congenital cataract is within the first six weeks of age, for unilateral disease(Birch et al., 1998), and within the first 10 weeks of life, for bilateral cases (Birch et al., 2009). Bilateral cataract presents a more favourable visual diagnostic as they cause less severe amblyopia than the unilateral cases (Birch and Stager, 1996, Lambert et al., 2006, Zhang et al., 2012). However, previous reports from various countries suggest that surgeries were significantly delayed for congenital cataract. In Paraguay, 97.3% of congenital cataract cases had surgery after 2 months (Zegarra et al., 2014) and similar delay was found in 95.5% in Brazil (Rafael Vidal Merula, 2005). In China similar results were

reported, with 98.8% of patients with lateral congenital cataract undergoing surgery after 6 months (You et al., 2011).

Visual outcome of congenital cataract has improved considerably, because advanced surgical methods and timely hospital presentation allow early cataract extraction with immediate optical correction and amblyopic treatment, which can prevent otherwise irreversible deprivation amblyopia (Hosal et al., 2000, Lambert and Drack, 1996). There is no direct correlation between age at surgery and adverse visual outcome in unilateral cases. The incidence of visual impairment and blindness in patients with unilateral cataract surgically treated after 3 years of age was not higher than in those treated within 3 years of age. This may reflect a need for treatment much earlier, and it was suggested that treatment during the first 6 weeks of life could achieve more favourable visual outcome for infants with unilateral cataract, and that this depends on the timely identification and diagnosis of the disease (Birch et al., 1993).

Some large scale population based studies have reported on the status of paediatric patients with delayed cataract surgery. Delay in presentation for surgery and poor post-operative visual outcome in paediatric patients remain challenging in low and poor income countries (Bronsard et al., 2008, Mwende et al., 2005, Yorston et al., 2001). Considerable variation exists globally. For example, no excessive delay was observed between medical diagnosis and surgery in Paraguay, whereas in Africa only 39% of children (Mwende et al., 2005) were surgically treated within 6 months of after having been diagnosed.

The ability of children's eye centres to address this issue is limited by the extent to which parents / carers use these services, social determinants being a major factor. In many instances it is the child's mother who first recognises any obvious eye defects in children. A study conducted in Brazil reported that mothers recognised 38.6% of the cases, suggesting that the health care system was not best placed to make an early diagnosis (Rafael Vidal Merula, 2005). Another study, from China, found that cataract was recognised within 6 months of age by caregivers in 40.7% of patients with bilateral cataract and 12% of patients with unilateral cataract, but surgery was performed in only 15.9% of patients with bilateral cataract and 1.2% of patients with unilateral cataract within 3 to 6 months of age (You et al., 2011).

Varied levels of outcomes were reported across studies from different countries. Most reported outcomes were poor with many children remain blind and severely visual impaired post operatively.

In China, the long-term visual acuity was unfavourable in approximately half of children diagnosed and treated for paediatric cataracts after 3 months of age. Visual impairment and blindness occurred in 41.4% of eyes, 52.0% of patients and contributing factors included age at presentation and absence of effective training for postoperative vision rehabilitation (Zhang et al., 2012). In Zambia, at 6 month follow up, 34.4% had BCVA of worse than 6/60 post operatively (Mboni et al., 2016). Visual outcome after congenital and developmental cataract surgery in children in Nigeria showed (53%) children had acuity within the normal range (6/6/ -6/18) post-operatively. The number of children with blindness (vision <3/60) decreased from 61 (92.4%) pre-operatively to 4 (6.1%) post-operatively (Duke et al., 2016). In Bangladesh, 53% were severely visually impaired or blind (VA <20/200) after a mean follow-up of 8.8 years. The reasons for this poor outcomes was found to be significantly associated with presence of nystagmus and the longer delay in presentation for surgery (Negretti et al., 2015).

In Nepal and India, 1 year after surgery, 53.5% had a normal visual status after optimal correction (range: 6/6 to 6/18) and 5.6% of children were still blind (Hennig et al., 2013). Another study from South India reported that after bilateral cataract surgery, over 30% of the children had an improved visual acuity post-surgery better than 6/18. However, poor outcome was found in children with congenital and total cataract; and at least half of the eyes had a visual acuity of >6/18 and the main factor associated with poor outcome was delayed surgery (Khanna et al., 2013). A study from Western India showed at 6 weeks follow up, almost half of the children had the distant vision better than 6/60 and aided near vision of N12 and above was seen in 75 eyes (68%) (Nikhil et al., 2016).

The incidence of poor visual outcomes increases if cataract surgery is delayed beyond 10 weeks of age and the absence of preoperative nystagmus is a better predictor of a good visual outcome than the age at surgery (Lambert et al., 2006). In Western India, at 6 weeks follow up after cataract surgery, the proportion of children who had post-operative visual acuity of 6/18 or better was almost similar (38%) in children presented early or delay for the surgery, suggesting that even in delayed surgery there is scope for gaining functional vision which may be enhanced with low vision devices (Gogate et al., 2010). Similar findings were

reported from Delhi and they found that vision improved in children until late childhood and recommended that cataract treatment is beneficial to all children, irrespective of their age (Ganesh et al., 2014). Consistent with this, acuity improvement after school age has been found in children with congenital cataracts (Magnusson et al., 2002).

1.5.1 Importance of postoperative follow up

Cataract surgery in children is only the first step of the long term complex visual rehabilitation program. Long term follow up care and continuous treatment is essential to achieve the full potential of visual rehabilitation. There are many known post-operative complications that can affect the visual outcomes even when the surgery itself was uncomplicated (Knight-Nanan et al., 1996, Vajpayee et al., 1991). One example is glaucoma after paediatric cataract surgery, which can cause serious visual impairment (Vajpayee et al., 1991). The incidence of glaucoma in children with aphakic eyes has been reported to be 5% to 41% (Magnusson et al., 2000, Rabiah, 2004), suggesting longterm follow up and screening for intraocular pressure after the paediatric cataract surgery, and it is highly recommended to prevent visual impairment and blindness (Baden et al., 2013).

Strabismus is a frequent complication post cataract surgery in children. Previous reports suggest that strabismus occurred in 63.9% of the bilateral cataract surgical cases and 29.6% of the unilateral cases and it is the major cause for achieving poor visual acuity post cataract surgery in children (David et al., 2016), and about 34.4% of the children in this study had strabismus pre operatively. Strabismus has a negative impact in many aspects of the individual's life like causing difficulty with self-image, securing employment, interpersonal relationships, school, work and sports (Satterfield et al., 1993).

Another significant complication that causes visual axis obscuration and disrupts the visual rehabilitation is posterior capsular opacity that leads to poor visual outcome (Hosal et al., 2000, Lambert and Drack, 1996, Lundvall and Kugelberg, 2002). The other complications such as intraocular lens rupture, endophthalmitis and retinal detachment, may also result in severe visual impairment.

In addition, a retrospective analysis from Hyderabad showed, in bilateral cataracts, the most common early post-operative complication was fibrinous uveitis in 57 eyes (13.3%) and the

most common delayed post-operative complication was posterior capsular opacification in 118 eyes (27.4%) (Khanna et al., 2013).

Follow up after cataract surgery is crucial to achieve the full visual potential in children, to check for complications such as those outlined above, and since the period of plasticity offers a limited time for successful treatment. However, the follow up rate in India and other developing countries after surgery is not very encouraging. Only 20% of the children had regular follow up with any hospital in Western India (Gogate et al., 2014a) and in South India the mean duration of follow up was 13.1 months (range: 3 – 38 months) (Khanna et al., 2013). In Mexico, the mean follow-up was 3.4 ± 1.8 months (Congdon et al., 2007). Previous studies have predicted various factors associated with good follow up rate after surgery in children. Early presentation for surgery and close proximity to the hospital were predicted for achieving better follow –up to post-operative services in Africa (Eriksen et al., 2006). Similarly, in Mexico, children living farther from the hospital made fewer postoperative visits (Congdon et al., 2007). In India, poor follow up was associated with older children and lower socio economic status of the parents. In addition, it was also highlighted that the importance of follow up was not communicated properly to the parents by the eye care practitioners (Gogate et al., 2014a). There is no literature available to support the duration of follow-up required post cataract surgery in children due to the variable needs of each individual child.

Only two publications to date focus on the visual outcomes after paediatric cataract surgery from India. A study from Maharashtra, in Western India reported that long-term visual outcomes in unilateral paediatric cataracts were poor due to deprivation amblyopia, but vision improved over preoperative levels and helped in achieving binocular stereo acuity (Gogate et al., 2014b).

Refractive correction and amblyopia treatment performed immediate to cataract surgery has been beneficial for improving visual performance in children. There is a strong correlation to the reduced incidence of visual impairment and blindness and the refractive correction and compliance of amblyopia training after surgery (You et al., 2011).

The above evidence suggests that continuous and comprehensive follow up is essential to identify the post-operative and other developmental issues on time and timely diagnosis and treatment would help to reduce the incidence of visual impairment and improve surgical

outcome in paediatric patients with cataract. A team approach is essential to achieve good visual rehabilitation for patients with paediatric cataract. The team includes the eye doctors, general paediatrician, community health professionals, orthoptists, optometrists, nurses and caregivers. All has to work together to provide comprehensive care before, during and after surgery, including the follow up care.

1.5.2 Importance of early treatment

While treatment of adult cataract is usually effective at any age, cataract that occurs in early life must be treated during childhood, and requires long-term follow-up. This is because the deprivation of visual stimulation caused by cataract prevents normal development of the visual system and if the cataract is allowed to remain during childhood, results in permanent visual abnormality known as amblyopia (Antonio-Santos et al., 2014b). Normal vision can be restored if therapeutic measures are taken at a sensory plasticity stage (Borisovsky et al., 2013, Lambert, 1999).

Both unilateral and bilateral cataracts are found in children. Both have significant impact on vision in different ways. Unoperated bilateral cataract has the obvious impact of reducing vision in both eyes, thus causing severe visual impairment and blindness. Unilateral cataract, on the other hand, has seemingly less impact, since it affects vision in only one eye, leaving the fellow eye able to provide unimpeded vision. However, it is important to note that bilateral visual deprivation during early childhood has a less severe impact on visual system development than unilateral deprivation (Birch et al., 1998). Adverse effects of dense congenital unilateral cataracts on the developing visual system of infants may result from the direct effects of visual deprivation and from competition with the normal eye in establishing cortical structure and function during a critical period in visual development(Birch et al., 1998).

The development of stereopsis takes place early in life. The first 6 weeks of life have been referred to as the precortical stage of visual development. Visual deprivation during this period of time is believed to result in amblyopia and disturb the development of binocularity (Lloyd et al., 1995). Previous research investigated the effects of deprivation by evaluating contrast sensitivity deficits in children treated for unilateral or bilateral congenital cataracts at various ages, and found visual loss to be greater in those treated at 12 weeks of age or older than in those treated at an earlier age (Simons, 1993). Although both groups of

children showed increasing deficits with increasing spatial frequency, those with a history of unilateral cataract had more severe deficits across a wider range of spatial frequencies than those with a history of bilateral cataracts.

Amblyopia caused by cataract is known as deprivation amblyopia, and if it occurs unilaterally, the non-deprived eye will gain ocular dominance, with greater representation in the visual cortex, and neurons tuned to binocular disparity (responsible for stereopsis) are lost (Zubcov et al., 1999).

Thus, prevention of blindness caused by congenital cataract depends on its early identification and management. This requires availability of specialist, appropriately equipped child eye care team at various levels. In high income countries availability of infrastructure and the early identification through new born screening is widely practised. In many such countries paediatricians and paramedical staff are involved in red reflex examination on all new-borns and it is repeated within the first three months of life (Fallaha and Lambert, 2001, Magnusson et al., 2003, Rahi and Dezateux, 1999). Early and timely detection of any lens opacity has been fulfilled by routine birth detection and professional follow up for decades in developed countries, which makes it possible for paediatric ophthalmologists to perform surgical intervention at the proper time. Previous reports suggest that late diagnosis limits the surgical treatment to achieve the best possible visual outcome (Chak et al., 2006).

In the United Kingdom (UK), 51% of bilateral congenital / developmental cataracts were detected during the first month of age. In developing countries, the ages at detection and at surgery were usually beyond 2 months of age, and delay to surgery was common (Chak et al., 2006, Fallaha and Lambert, 2001). The possible reasons for the delayed diagnosis include non-existence of new born screening program, lack of knowledge among the parents /caregivers, limited accessibility to specialist centres and most importantly the cost of services. Lack of general screening at birth and lack of knowledge of paediatric eye diseases by community medical practitioners and children's caregivers contributed to the delay in presentation to a professional eye centre for therapy, and thus development of visual impairment (You et al., 2011).

In most developing countries the number of children with cataract being brought to hospital for surgery has been less than the burden of the disease in the community. Best estimates suggest that, in settings with no specific programs to identify and refer children with cataract, there are likely to be around 100 children with cataract per one million (total population), with 20 – 30 children per million born each year (Courtright et al., 2008).

An active program for the detection of congenital and infantile cataracts does not exist India. Currently, children with cataract in the country are identified when they present to an eye care program. Surgery for cataracts in children is performed primarily by ophthalmic surgeons trained for adult cataract surgery and by some ophthalmic surgeons trained in paediatric ophthalmology. Surgery for cataracts in children is performed at the tertiary eye care level in the non-government organisation (NGO) sector, at some of the secondary eye care centres especially teaching ophthalmic units in the government sector, and by some ophthalmologists in the private sector (Murthy et al., 2008).

1.6 Delayed presentation for childhood cataract surgery

Relatively few studies have been published about the delayed presentation for childhood cataract surgery and almost all of them were based on retrospective hospital based reports. In Tanzania, the mean delay between recognition by the caregiver and presentation to hospital was 34 months, and the median delay was 9 months for congenital cataract and 24 months for developmental cataract. In this study the long delay was associated with having developmental cataract, living far from the hospital, and low socio-educational status of the mother and children with congenital cataract, having another sibling increased the likelihood of early presentation (Mwende et al., 2005).

In China, a retrospective analysis showed the mean ages at disease recognition and at surgery were 22.6 ± 30.4 months and 68.3 ± 40.0 months, respectively. Although 53% of the cataracts were recognised within 6 months only 17% underwent surgery between 3 and 6 months of age suggesting that delay in cataract surgery happens even after recognition (You et al., 2011). Another retrospective study from Madagascar, the presentation at surgery was further delayed with the mean age at presentation 6.9 years (±SD 4.3) for congenital cataract and 13.1 years (±SD 2.9) for developmental cataract (Randrianotahina and Nkumbe, 2014).

In India two retrospective studies from South and West India reported similar to the above data. In the South, the mean age of presentation to the hospital was 53 months (range: 0-168 months) and mean age at surgery was 55.2 months (range: 1-168 months) for childhood cataract (Khanna et al., 2013) and in the Western region, almost in 46% of the cataracts the presentation for surgery were delayed and in most of the cases the delayed period ranged from 5 years to 13 years (Gogate et al., 2010).

1.7 Barriers to access childhood cataract services

Parents as primary care givers make decisions on seeking health care service for their children (Glascoe, 2003). Understanding parents' perception and awareness of eye problems is important in understanding and delay in accessing services by parents. Cataract tends to be associated with old age and the awareness among the parents and families about childhood cataract was poor. Lack of awareness was reported as the major reason for not accessing children's cataract services in developing and under developed countries (Bronsard et al., 2008).

A study from Bangladesh revealed that half of the parents interviewed believed that childhood cataract is untreatable and only 5% sought treatment from an ophthalmologist (Muhit et al., 2011). Another qualitative study from rural south India reported that parents and family predominantly believe that the children below 4 years should not wear spectacles. Strabismus was considered as untreatable and was seen as a sign of good luck. In this study it was stated that eye doctors were approached last for eye care, after traditional healers and general physicians (Nirmalan et al., 2004).
These findings reinforce the necessity of parental awareness of common eye diseases in children and the importance of seeking timely advice including treatment based on informed decisions and the need to involve communities at every stage of eye care programs.

Various factors has been reported as barriers to accessing childhood cataract services predominantly distance and cost of travel to hospital. These two reasons were reported in many countries including Zambia (Mboni et al., 2016), Malawi (Schulze Schwering et al., 2014) and India (Gogate et al., 2014a, Balasubramaniam et al., 2013). Other important barriers reported include lack of understanding of cataract as a cause of blindness and impairment, and possible treatment options by the decision makers in the families.

In Africa, gender relations within the household, local health beliefs about cataract and cataract surgery and the inability of health care professionals in primary and secondary care settings to adequately inform parents and guardians about cataract and cataract surgery were reported as barriers (Bronsard et al., 2008). However, data from parents suggest several barriers to understanding, including the large amount of information, stress, and preoccupation with the child and parental unrealistic optimism about risks and outcomes (Erraguntla et al., 2012).

These findings highlight that just providing surgery free of cost may not be sufficient for the most economically disadvantaged and increasing awareness, training of health workers at the primary level and counselling in the communities to facilitate better eye health-seeking behaviour may be necessary to enable children to access services in a timely fashion.

1.8 Studies from India on Childhood cataract

1.8.1 Report from schools for the blind

There is a paucity of epidemiological data on childhood blindness, essential for setting priorities and policies, in most developing countries including India. As stated earlier, most of the estimates on childhood blindness are based on data collected from schools for the blind from developing and under developed countries. The first multi-state study conducted in India collected data from 22 schools for the blind from nine states in the country and found that the majority of the children suffered blindness due to avoidable causes, with 12.3% of the cases due to cataract, uncorrected aphakia and amblyopia (Rahi et al., 1995b). In the same study, the authors reported that severe visual impairment and blindness due to vitamin A deficiency ranged from 7.5 % to 26.7% in different states and within the same state it was as high as 30.4% in rural areas compared to 7.5% in the capital city suggesting marked variations by state and also between urban and rural locations within the state (Rahi et al., 1995a).

Another study conducted in a single state (Andhra Pradesh) covering all six schools for the blind also reported 37.4% of the children had avoidable causes of blindness and among those vitamin A deficiency and cataract were the major causes (Hornby et al., 2000). Similar findings were reported from a study covering schools for the blind in North India (Titiyal et al., 2003). A more recent study from a school for the blind in the state of Andhra Pradesh reported that 41.4% of the children enrolled had congenital eye anomalies of which 9.7%

(95% CI: 2.9-12.9) were due to cataract (Krishnaiah et al., 2012) and similar findings of high congenital anomalies in children were reported from Maharashtra (Gogate et al., 2007).

Also, it was evident from the reports that visual impairment was high among the children after cataract surgery and they were admitted in schools for the blind, despite they could benefit from refraction and low vision services (Pal et al., 2006). The research findings above indicate that there is room for improvement in the timely treatment of childhood cataract in developing countries, including surgery and post-surgical care.

1.8.2 Population based studies

To estimate prevalence of childhood blindness in the population requires large sample sizes given the low expected prevalence rates of approximately 5 – 8 per 10000 children. Population based estimates are very cost intensive and hence only three population based studies in India have been published to date, all from the Southern region of the country. In one study (Dandona et al., 1998c) cataract was found to be one of the major cause of avoidable blindness in children in this region. The authors indicated that the high proportion of consanguineous marriage in this population could attribute to this high prevalence of congenital anomalies in children in this region.

A second study reported that, in Tamilnadu, 42.9 % of the blindness in children was avoidable or treatable, with refractive errors and strabismus found to be the major ocular morbidities in children (Nirmalan et al., 2003) and 5 per 10,000 children were estimated to have blindness caused by cataract in this population.

Another study from rural south India reported that the prevalence of childhood blindness was 1.06/1000 (95% CI, 0.50 to 1.61), and that of these 42.9% had lens and related complications (Dorairaj et al., 2008b). In this study consanguineous marriage was reported in 71.4% of parents of blind children and 83.3% of parents of children with cataract. From this same population the prevalence of unilateral visual impairment in children was reported to be around 1.13 in 1000 children with major cause as amblyopia due to uncorrected refractive errors (Bandrakalli et al., 2012).

All of the above three studies aimed to estimate the prevalence and causes of blindness in children based on visual acuity in the better eye, hence it is likely that unilateral cataracts

and mild cataract not significantly affecting visual acuity will not be covered. This suggests these estimates are very conservative and there are no population based reports aimed at estimating childhood cataract in India.

India has the second largest population in the world and has diverse demographics. Its health care system varies across the country with each state government being responsible for the health care of its own population. Consequently, availability and utilization of health services as well as availability of health care resources differ between states (Purohit, 2004). Eye care is provided by different types of organization, including government hospitals, and non-governmental organizations (NGOs), the latter including 'not-for-profit' and private hospitals. Each of these has different policies and practices regarding the fee structure. For example, government provision is free to all users, while not-for-profit hospitals charge fees on a sliding scale based on each individual's ability to pay, and private hospitals charge relatively high fees, which apply to all patients (Murthy et al., 2008). Overall, 65% of the eye care services in India are currently offered through NGOs including not-for-profit and private hospitals (Xiao et al., 2014). These factors combined with population diversity provide scope for significant health inequity (any difference in the "presence of disease, health outcomes, or access to health care between populations with a different race, ethnicity or socioeconomic status" (Kawachi et al., 2002)) and any study conducted in India needs to cover a wide geographical region to allow meaningful comparison.

Based on the above literature review, it is evident that there is a lack of information on the epidemiology of childhood cataract and also there is lack of clarity on the delayed presentation at the hospital by children with childhood cataract. Furthermore parents' knowledge and experience of childhood cataract and related services has not been studied in this population, and is a crucial first step in understanding the factors contributing to delayed presentation. The aim of this research was to determine the extent of delay for childhood cataract surgery and to investigate the factors contributing to delayed presentation of children with cataract, both from the perspectives of parents and the primary eye care providers.

1.9 Structure of this thesis

The thesis comprises seven chapters, including this introductory chapters, five empirical chapters and a summary chapter. Chapters' three to six are presented as separate reports with brief introduction, detailed methods, results and discussion and referred and linked to other chapters where appropriate. In the present chapter, a narrative literature review is focused on childhood cataract, its causes and the importance of early surgery in children, and the research question within existing knowledge of childhood cataract service delivery in India.

Chapter Two focuses on the mixed methods approach used in this thesis, describing in detail the specific methods and analytic approaches used in the quantitative and qualitative phases of this study.

Chapter Three focuses on a systematic review to estimate the global prevalence and incidence of childhood cataract and the burden of childhood cataract in India. The results highlight the knowledge gaps in this topic in various geographic regions.

In Chapter Four, quantitative data obtained from parents and hospital records are presented, and were used to estimate the age at presentation for childhood cataract surgery in regions across India, and socio demographic factors associated with the delayed presentation of congenital cataract surgery.

Chapter Five, describes a mixed method study in which barriers and enablers for childhood cataract services from the perspectives of parents' and carers are identified using a Theoretical Domains Framework (TDF). The key TDF domains identified as barriers and enablers are listed and sub themes associated with each domain are identified and discussed.

In chapter Six, primary eye care providers' perspectives on their knowledge and the barriers to childhood cataract services are presented and discussed.

In the final chapter (Chapter Seven) the significance of this study's findings are highlighted, specifically discussing implications for further work and making key recommendations for screening for childhood cataract, the development of implementation programs with

theoretical underpinning, the delivery of health promotional activities and the development of wider public policy.

Chapter 2

2 Methodology

Summary

In this chapter, the mixed methods approach that was used in this research is described. An introduction to mixed methods research leads on to the rationale for adopting this approach in the present project. This chapter also discusses the analytical approach adopted for analysing both quantitative and qualitative data in this research.

2.1 Rationale for adopting mixed methods

The primary research question posed in this research are: What factors (both barriers and enablers) are associated with access to childhood cataract services in India? The uptake of childhood cataract services may be prevented by factors affecting parents/carers and health care system. For example, eye care services may be limited in terms of its infrastructure and facilities, and parents may be unaware of the impact of the disease on their child, or unable to access the service due to various reasons. The four main questions posed in this research are:

1. What is the period of delay between first recognition of an abnormality, (by the parents/caretakers/primary level staff) accessing an eye care facility and surgical intervention in India?
2. Are there any regional differences in barriers and enablers for childhood cataract?
3. What are the barriers perceived by the parents/caretakers between first recognition of an abnormality and accessing a surgical intervention?
4. What are the barriers perceived by the primary care providers for accessing the childhood cataract services by the children?

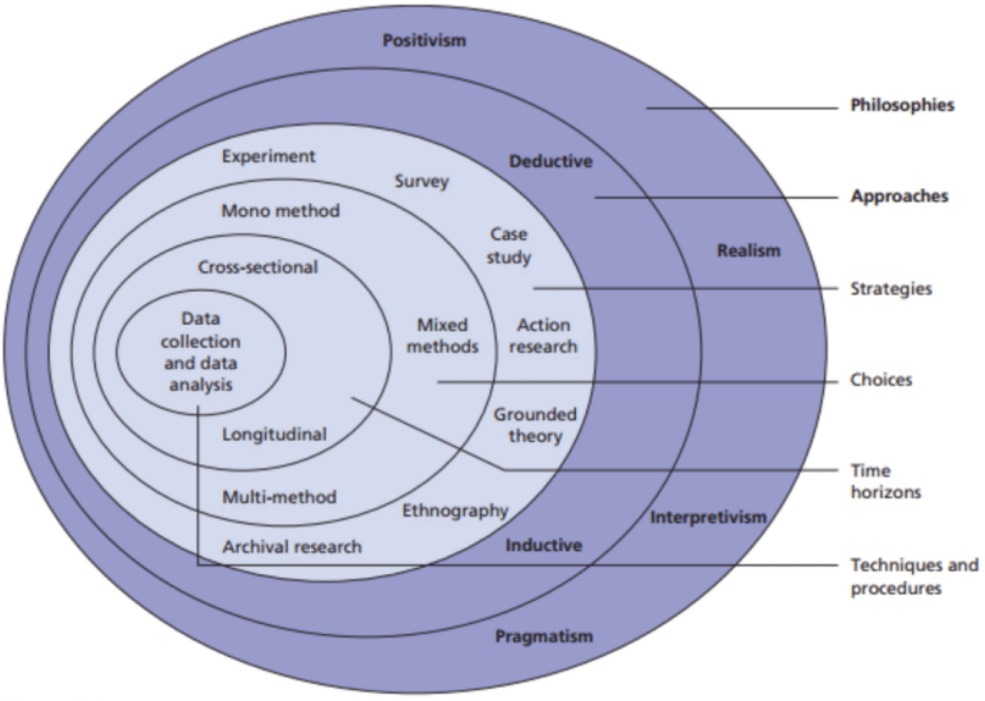
On addressing these questions, the research aims to develop an intervention strategy to address these barriers based on behavioural change psychological theories.

Understanding the period of delay in childhood cataract services involves obtaining data from hospitals related to the child's age at the time of cataract surgeries. This requires a quantitative approach of collecting and analysing the numerical data. Whereas, understanding barriers from the perspectives of parents and primary care providers are multidimensional and require an in-depth approach. Given the complexity of information involved in this research, both quantitative and qualitative methodologies were adopted to answer the specific research questions in this research.

2.2 Research Strategy

The research strategy describes how this research been conducted and gives a general orientation on the logical approach in answering the research questions (Bryman, 2001). The research strategy was developed using the Research Onion (see Figure 2.1) model as a reference (Saunders, 2012). This approach gives clarity on the various layers involved in any research and provides clear guidance for selecting the appropriate strategy for answering the questions pertaining to the individual research.

Figure 2.1 Research onion, the six important layers in finalising the research strategy (exact copy of Saunders 2009)



The first step in any research is to determine the theoretical basis for the research so that the researcher knows whether they are working inductively or deductively (Creswell, 2007a). This is usually determined based on the research question. For example, in this research, the researcher is interested in the quantum of delay in accessing the services and mainly to focus on the issues and experiences of the individuals associated with this delay using a deductive approach. Further to the data collection, the findings are interpreted to understand and make an impact on this issue of addressing the delay in accessing the childhood cataract services.

Theoretical approach to mixed method research

Both quantitative and qualitative research methods are popular in the social, behavioural, and health sciences, in which researchers collect, analyse, and interpret the findings. In general, quantitative and qualitative research are distinct and are based on different philosophical principles.

Newman categorised the research methodologies into two major approaches (Neuman, 2006): quantitative (positivist) and qualitative (post positivist). Quantitative research is based on the idea that it is always possible to understand the reality based on objectives measures (Casebeer and Verhoef, 1997). Using this approach the research aims to explain, predict or control factors in order to discover some objective truth. Quantitative research uses numbers rather than words and it offers scope for collecting data from many participants on a number of well-defined questions. In general, quantitative methodology is objective, deductive, theory driven and generalizable to larger population (Hammersley, 2002).

Qualitative research is based on an constructivism model which assumes that human beings construct their own realities based on their physical and social experiences (Henwood and Pidgeon, 1992). This type of research method takes an interpretive approach to study people and situations within a natural setting or in a manipulated setting (for example, at hospitals). It is an interactive process in which the researcher and the participant learn from each other and results in realistic understanding, which is interpreted based on the social and cultural context of their lives (Lincoln, 1985). Qualitative inquiry is based on an inductive

reasoning process where the research design process evolves, such that the questions asked and the data to be collected emerge in the process of doing the research. In-depth, detailed, rich data is produced based on the individual's personal perspectives and experiences (Henwood and Pidgeon, 1992). The goal of qualitative research is the development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of all the participants. In general, qualitative methodology is subjective, inductive, and not statistically generalizable (Hammersley, 2002).

2.3 Mixed methodologies in public health research

There has been an ongoing debate on which methodology to use in health research. Both positivist and post positivist approaches have many advantages and disadvantages. Rather than focusing on a single approach, both approaches can support each other in the development of theory. This combination is known as mixed methods research and has gained acceptance in the fields of sociology, health and education (Creswell, 2007a). The main principle of mixed methods research design is that the combination of quantitative and qualitative approaches provides a better understanding of the problem studied compared to either one of the approaches. Moreover, it allows the researcher to use a wide range of data collection tools to conduct a comprehensive research on the chosen topic.

2.4 Mixed methods in the context of the present research

As discussed earlier in this chapter, this research aimed to explore the complex, multidimensional nature of issues affecting access to childhood cataract services in India. The three specific research questions encompass the age at which childhood cataract surgery happens in India, and the barriers to treatment from the perspectives of both parents and the primary eye care providers, necessitating a mixed methods approach.

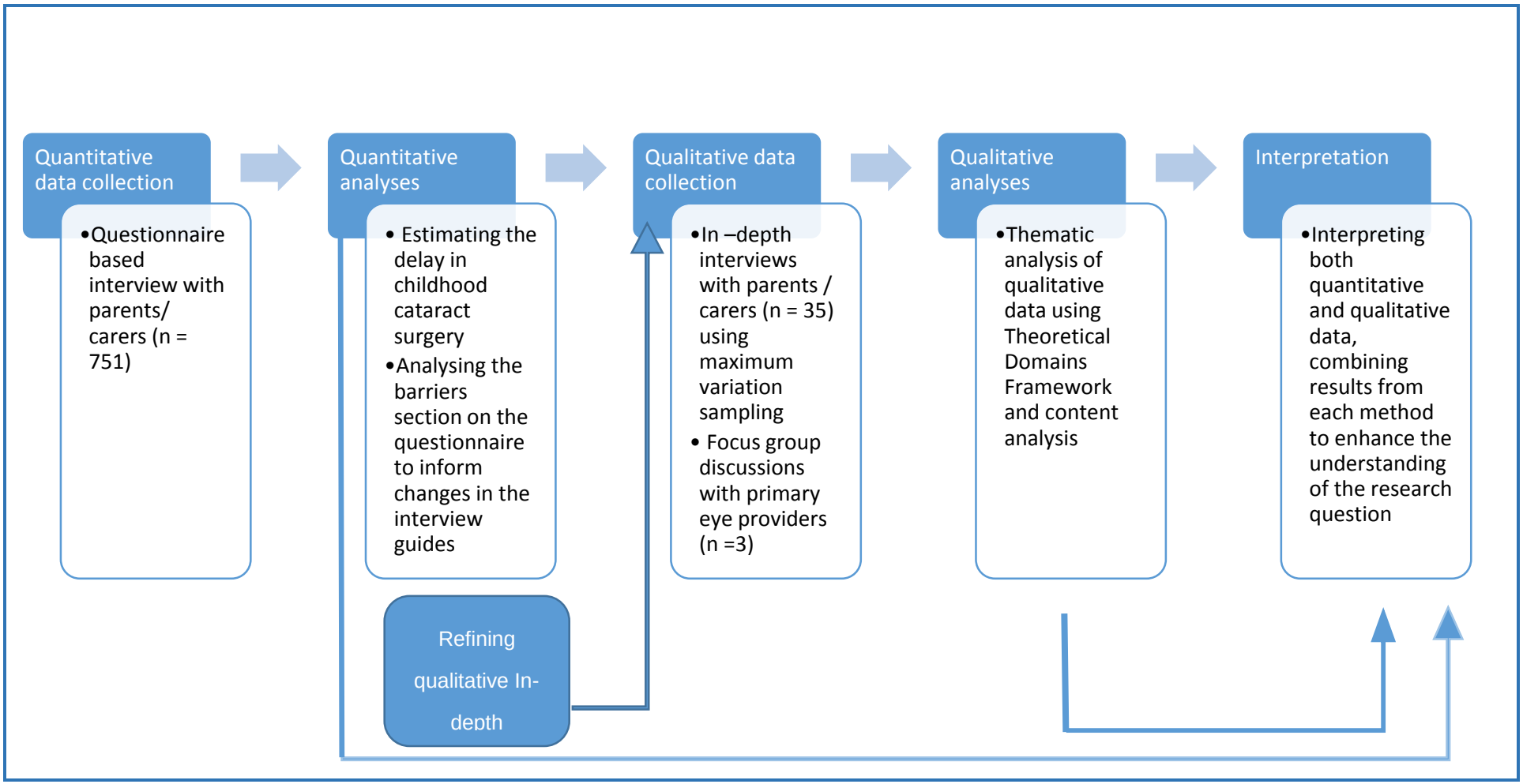
The research design is based on a sequential explanatory model with a quantitative phase followed by a qualitative phase (Creswell, 2007b) and the overall study design is summarised in Figure 2.2. The first phase of the study was collecting the quantitative data from parents and carers at each of the nine hospitals participating in this research. These interviews were conducted by trained interviewers from each hospital at which the child is

admitted for cataract surgery. The quantitative questionnaire included a section on barriers to access services and the responses were recorded on a 5 point Likert scale (more details about the questionnaire are provided later in this chapter). Responses in this section helped to identify areas for more exploration in the qualitative phase of the research. Based on the initial analysis, modifications were made to the in-depth interview guide, mainly to explore issues related to cost, decision making and access to eye care facilities.

This was followed by the qualitative phase of data collection which sought to explain and contextualise the findings from the quantitative data. The qualitative phase comprised of in-depth interviews with randomly selected parents / carers from all the participating centres and focus group discussions with the primary eye care providers. Each dataset was maintained and analysed independently using appropriate techniques as explained in the analysis section in chapter five and six.

Although mixed methods research is increasingly recognised in the field of health research, such an approach is relatively new in eye care specifically.

Figure 2.2 Mixed methods design for this study



2.5 Quantitative methods

The quantitative phase of this study involved a survey among the parents and carers using a questionnaire developed for this study. In this study, one aim was to ascertain the extent of delay in accessing cataract surgery by children across India. To collect these data a quantitative survey was designed. The questions were included based on the existing literature aimed at determining the delay in accessing childhood cataract services (Mwende et al., 2005, You et al., 2011, Gogate et al., 2010)and studies focused on understanding barriers to utilisation of existing eye care services (Gogate et al., 2014a, Bronsard et al., 2008, Muhit et al., 2011). The summary of previous studies in these two areas were discussed in Chapter 1.

Questionnaires can be used to collect data, opinion or views from a group of respondents to address a research question. Increasingly many studies use a validated standard published questionnaires to overcome logistics constraints. However, developing a standardised questionnaire for data collection itself involves detailed research, so given the time constraints the standardisation of questionnaire was not attempted in this research. For this research the questionnaire was developed based on the research objectives and by reviewing the previous questionnaire used for the assessment of barriers to cataract surgery. However, most of the previous studies focused on barriers were conducted in adult population and hence the researcher adopted following three steps while designing the questionnaire for this research.

1. Various questions to be asked to find answers for each of the study objectives were listed. This step was crucial and a few brainstorming sessions were conducted to list out all possible questions that need to be asked during the data collection. Brainstorming is a group activity within the research team and several sessions were held to identify and list all possible questions that need to be answered for each specific objective. The team reviewed together a few times both independently and collectively. This helped the team to ensure whether questionnaire was the appropriate tool for collecting the information required (Marshall, 2005).

2. Selecting of question type for each questions and the exact phrase to be used

3. Designing the question sequence and overall layout of the questionnaire before piloting.

The questionnaire had five major sections including:

1. Socio demographic details including parents' ages, education levels and occupations.
2. Child's demographic details such age, gender and birth order
3. Child's age at cataract recognition and assessment
4. Methods of cataract recognition and assessment?
5. Barriers to access hospital and to surgery
6. Surgical data including date, type of surgery, surgery eye and diagnosis etc.

The questions 1 to 4 were recorded while interviewing the parents /carers on any one of the three days the child was admitted at the hospital to undergo cataract surgery and the last section was completed based on the details recorded in the hospital medical records.
All the questions were worded carefully, without any ambiguous statements designed with different types of questions. The complete questionnaire used for the main study is attached as annexure xx and given below are examples of different type of questions being used in this research.

1. Numerical rating: A Likert scale from 1 – 5 was used (1 – low importance to 5 – High importance) and the respondents were asked to give a rating for their response for a specific question from based on their individual perspectives. This method allowed us to evaluate the severity of the barrier experienced as reported by the respondents. For example, if the surgery was delayed due to unavailability of hospital appointment, the respondent has to give a rating between 1 and 5 to indicate the extent to which this influenced the delay in accessing the services.

2. Multiple choice: the respondents were required to choose one response from a list of alternatives if the questionnaire is completed by the respondent themselves or it would be marked by the interviewer as per the respondent's response. For example,
At what age was the child's eye problem identified?

a. Within 1 month from birth
b. 1 -6 months

c. >6 -12 months
d. >1 -3 years
e. >3 -10 years
f. Above 10 years

Of the total six possible answers one would be chosen by the participant. Also, wherever necessary, an extra option to specify others were included. For example,

1. Whom did you see first for your child's eye problem?
    a. General physician
    b. Paediatrician
    c. Ophthalmologist
    d. Others (please specify……..)

3. Check list: the respondents were given set of items to select all those applicable to them. For example, a list of all possible barriers from which the respondents were asked to select all those applicable to them.

The questionnaire was developed in English and after finalisation it was translated into regional languages with the support of external language experts.

2.5.1 Pilot study

A pilot study is considered as a "small scale version or trial run in preparation for a major study (Polit D.F, 2001). A pilot study tests the questionnaire to determine if the items included are receiving the kind of information that is needed (Baker, 1993) and does not include misleading, inappropriate, or redundant questions. Whenever pilot testing is done, it is important look out for a failure to answer particular questions, or multiple answers to the same question (Fink, 1985) suggesting that the instrument needs revision.

The main advantages of conducting a pilot study personally to a small group of respondents is that it helps the researcher in fine tuning the research instrument and to ensure that the questionnaire met the objectives of the proposal and that the language is understandable to participants and relevant to the population. In this research, the questionnaire was developed in English and it was first piloted in one regional language with 15 parents and carers who had presented at the hospital for their child's cataract surgery or for post-operative follow-up. The interviewer and the principal researcher met with the consented subject in the inpatient

rooms or at the waiting area and explained the purpose independently to each parent or to the family members presented at the hospital. The researcher read the questions to the parents one by one without any explanation and recorded the responses. Some questions were found to be confusing. For example, there was a question relating to the total amount of wages lost for coming to this hospital for cataract surgery. In some families both parents and other members in the family had lost income and in others only one. In the initial instrument there was no mention about the number of people for whom the wage loss applied. In the further revision, it was modified to include the number of people and their wage loss details. In the original questionnaire, for the question 'At what age was the child's eye problem identified?' the response options were not mutually exclusive, meaning that more than one option might apply. This could create complications in analysis, so the options were modified. Also, in the clinical data, questions related to diagnosis, probable cause and type of surgery were open ended. To simplify data analysis, in the revised final version, these questions were closed ended with the option to tick the suitable answer and if in case the answer does not fit with the existing one, 'others' option was given to record the details.
Translation of the instrument into multiple languages creates the possibility of dis-similar meaning in different language versions. With this in mind, as outlined earlier the questionnaires were back-translated, and pilot testing of the instruments in all languages was conducted before the main study.

Also, this pilot process helped the researcher in ensuring that all the questions included in the questionnaire received a response from the participants. The data from the pilot study were not included in the final analysis.

2.5.2 Validity and reliability

Validity of the questionnaire is "the degree to which there are systematic differences between the information obtained in response to the questions relative to: full meaning of the concept; related questions about the same concept; and theories or hypotheses about their relationship to the concepts" (Lu Ann Aday, 1996). For this research both face validity and content validity measures were applied. Although both the measures are subjective in nature, (Lu Ann Aday, 1996) both the assessments are generally performed by the subject area and research experts. Hence, these measures adequately ensure whether the questionnaire was able to measure what it was intended to measure.

Face validity was measured by circulating the draft questionnaire to five experts in the field and their feedback and comments on the questionnaire were reviewed and necessary modifications were made before finalising the questionnaire. Similarly, the experts were asked to review the content used in the questionnaire and all of the experts unanimously agreed with the suggested items and felt that the items were relevant and consistent to answer the objectives of this research.

When the questionnaire developed to measure a particular concept and assesses the same concept over time on repeated testing and both responses and outcomes are consistent and similar even the questionnaire is administered by different researchers, then the questionnaire developed is considered to be reliable (Carmines and Zeller, 1979). However, reliability measures are more useful if the questionnaire collects quantitative data. For example, visual acuity measurement in the children would allow an estimate of reliability of the assessment by different examiners. No such quantitative measure was used and an inter-rater reliability test was not performed. The reliability of the data collected was assessed by checking the medical records and matching the questionnaire for basic socio demographics and clinical information in all cases. In addition, 10% of the total interviews conducted in all 9 locations were attended by the researcher to ensure the quality of information being collected.

2.5.3 Sample size

The sample size for this study was determined based on two factors. The study uses non-homogenous multiple data collection points which introduces a design effect, see page 48. This source of variance had to be balanced against practical limitations such as time and other resources, so the sample size was calculated based on the type of analysis proposed and the estimated response rate for this survey. The main analysis proposed for this quantitative survey was to calculate the proportion of late presenters for cataract surgery across different study centres. Also the estimated response rate from the parents was 80%. This estimation was not powered to detect the presence of risk factors for late presentation.

Previous studies from developing countries (Mwende et al., 2005, Gogate et al., 2014a, You et al., 2011) have reported that approximately 50% of children with cataract do not present sufficiently early for treatment. Therefore, for the purpose of this research we assumed that

late presentation rate of 50% with 95% Confidence interval with 5% precision rate and calculated our sample size as follows:

Sample size estimation (n) (Lwanga SK, 1991) = $z^2 \times p(1-p) \div c^2$

Where:

z =1.96 (for 95% CI)

c = precision 5%

P = late presentation proportion

Sample size, n, calculation

$n = (1.96)^2 \times 0.5(1 - 0.5) \div 0.0016$

$= 3.8416 \times 0.5 (0.5) \div 0.0016$

= 600.25 + 20 % (refusal rate)

= 720

A total of 720 children undergoing cataract surgery was therefore required for this study. The nine participating hospitals' data over the previous two years were reviewed to estimate the number of months over which to recruit the estimated sample.

The centres included in this study varied in terms of demographics and the number of children undergoing cataract surgery. Therefore, considering each dissimilar centre as a cluster introduces a design effect and influences the power of the study (the probability of detecting a difference when one exists). The design effect is taken into account in sample size calculation, to ensure adequate statistical power. However, a larger sample size increases the chance of finding even a smaller difference to be statistically significant, so it is important to determine what would be a meaningful difference before performing a power analysis to determine the actual sample size needed.

Considering the variance in the volume of care across nine centres it was proposed to complete the recruitment for this research over a period of 4 months from mid-November 2015 to mid-March 2016. All the parents / carers whose child was admitted for cataract surgery during this four month period were invited to participate in this research.

2.6 Qualitative methods

2.6.1 In-depth interviews

As outlined earlier, qualitative research is a form of inquiry that analyses information conveyed through language and behaviour in natural settings (Berkwits and Inui, 1998). Such methods are preferable when the investigation is oriented to determine motivation, perceptions or beliefs. There are many qualitative methods used in health research including observation, focus group, in-depth interviews, consensus method and case studies, however, both focus-group and in-depth interview are among the most used methods (Gill et al., 2008). This method is considered appropriate for addressing sensitive topics that people might be reluctant to discuss in a group. For example, some parents may not willing to discuss their child's eye condition when others are around or they may be hesitant to discuss any personal financial issues which caused the delay in accessing the services.

In-depth interviews are most appropriate for situations in which key open-ended questions are asked to elicit depth of information from relatively few people (as opposed to surveys, which tend to be more quantitative and are conducted with larger numbers of people) (Rosenthal, 2016). In depth interview is an effective qualitative method for getting people to talk about their personal feelings, opinions, and experiences as they are open-ended and discovery-oriented, allowing the interviewer to deeply explore the participants' perspectives on a subject. This results in rich background information that can shape further questions relevant to the topic. In this research, the researcher was interested in understanding the "why" behind peoples' behaviours or actions in accessing childhood cataract services. Hence it was decided to apply an in–depth interview method to elicit responses from parents and carers.

The quality of the data received from an in-depth interview depends upon the level of thought put into the development of the questions posed to the interviewees. There are six recommendations for designing open ended in-depth interview questions / guides (Patton, 2002). The discussion should primarily cover (1) experience or behaviour questions, (2) sensory questions (whether they heard, seen, felt etc.), (3) opinion or value questions, (4) knowledge questions, (5) feeling questions (emotional), and (6) background or demographic questions. This set of pre-planned questions serves as a useful guide to the researcher. However, it is important that the interview is more conversational, with questions flowing from previous responses when possible to clarify and interpret throughout the interview (Sandy Q.

Qu, 2011). The in-depth interview guide prepared for the present study is discussed in detail in chapter 5.

In addition to the preparation of the interview guide, obtaining good quality data from the interview depends on the interviewer's preparation and the way the interviews are conducted. The interviewer should be well prepared and have good conversational skills to facilitate the interview. Also, it is important for the interviewer to establish good rapport with the participants at the beginning of the interview to make the participant comfortable throughout the interview for effective data collection (Kvale, 1996). Keeping the interview guide as a reference, the interviewer has to use different questioning methods starting from broad questions to more focused ones and to use probing techniques to explore the answers given by the participant in detail without intimidating or guiding the participants. For successful data collection through this method, it was recommended for the researcher to be familiar with the techniques informed by the literature, followed by having 'hands on' experience of these techniques through practice sessions (Patton, 1987). Also, it is important to understand there are many factors which inevitably differ from one interview to another and hence the interviewer should be sensitive to individual situations and allow flexibility in different interviewing circumstances.

The interviews were conducted in a private room within the hospital to make the participant feel at ease during the discussion. The questions were asked in their local language and if the participants were not able to follow any of the questions, the local hospital co-ordinator explained them again using local dialect for better clarity. Rapport was established with the participants using different approaches including attentiveness during the discussion, showing courtesy and empathy and engaging the participant throughout the discussion.

The next important step in the research process is to determine the appropriate sample size for in-depth interviews or focus groups. The purpose of any qualitative research is to develop an understanding of the meaning behind behaviours without aiming for generalisability. Therefore the sample for qualitative interviews aimed at balancing between the need to obtain a rich experiential description from interviewees, with the emphasis to have equal representation of experiences across the population of possible participants (Patton, 2002). Compared to quantitative design, calculating the required sample size is very different. Although there are no hard rules for calculating the sample size for qualitative studies, the

literature recommends reaching saturation or redundancy of the data being collected. In general, the data collection is discontinued when the data achieves the saturation point which is, when there is no new information being generated (Mason, 2010).

A stratified purposive sampling technique was used to select the participants who had experience in accessing cataract services for their child and face to face interviewing was conducted with the parents who gave consent. The interviews were conducted in local languages for the convenience of the participants to express their feelings openly and the entire discussion was audio recording for further analysis.

2.6.2 Focus group discussion with the primary eye care providers

Another aim of this research was to understand the perspectives of the primary eye care providers on access to cataract services by the children. Primary eye care providers include trained community eye care workers (CEW) and vision technicians (VT). The community eye care worker works in the community to screen the population for various eye diseases and to act as a link between the community and the hospital. They work within the community to promote awareness on better eye health practices including motivating the parents of children with eye problems to visit the eye hospitals for further treatment. The vision technician is qualified by training for the primary eye care centres to provide screening and identification of major blinding eye diseases, refraction and provision of referral services to the next level of care. The VT also engages in constant communication with parents in motivating them to take their child to the next level of care. Similar cadre of human resources are mostly available within non-governmental organisations across the country. Hence, understanding knowledge and perspectives of this group would help in addressing the children's eye care issues in the future.

An aim of this research was to understand the barriers to accessing cataract services by the children from the perspectives of parents and carers. However, to complete the understanding and to achieve triangulation, provider perspectives is an integral component and hence this group of eye health professionals were considered for this research. Considering the importance of providers' perspectives in this research and based on time and logistical constraints, a suitable method was adopted for collecting data from this group.

The aim was to collect qualitative data capturing the experiences of the participants in the subject area of this research and to explore perspectives that can provide invaluable guidance for identifying factors that can contribute to solve some of the issues currently faced. Focus groups are viewed by social scientists as a flexible and cost effective method for exploring attitudes, experiences and responses of non-random samples of people who fit a particular profile (Sofaer, 2002) and many researchers have suggested the focus group as a tool for collecting qualitative data (Morgan, 1996). However, focus groups can be used either independently in qualitative research or in combination with other methods, including quantitative techniques.

In general, focus groups are useful for 1. Discovering new information (for example, about a new product or service) and consolidating existing knowledge 2. Obtaining a number of different perspectives on the same topic, in the participant's own words 3. Gaining information on participant's view, attitudes, beliefs, responses, motivations and perceptions on a topic; 'why' people think or feel the way they do 4. Examining participants' shared understanding of everyday life, and the everyday use of language and culture or particular groups 5. Brainstorming and generating ideas, with participants discussing different angles of a problem, and possibly helping to identify solutions 6. Gaining insights into the ways in which individuals are influenced by others in the group (group dynamics) 7. Exploring controversial issues and complex or sensitive topics (Litoselliti, 2003). Since this method of data collection was considered appropriate for obtaining qualitative data from the primary eye care providers, focus group discussion was planned for this research.

Focus group discussion (FGD) is defined as a "research technique that collects data through group interaction on a topic determined by the researcher" (Morgan, 1996). Being a group interview based research approach, a focus group requires someone to interview the participants as well as provide guidance in the position of a facilitator, commonly called as moderator (Berg, 2001). The group consists of 8 – 12 members and the discussions are usually conducted in a quiet environment where the participants feels comfortable without any external disturbances and the entire discussion is usually audio taped for later transcription. Usually the number of focus groups are not pre-determined and was are continued until the data saturation is reached (Francis et al., 2010).

The role of moderator is of critical importance in facilitating the discussion (Litoselliti, 2003, Morgan, 1996). The main role is to guide the group's discussions but not participate in them (Krueger, 1998). This means that moderators do not share their views about the topic(s) being studied or engage in the discussion; rather their role is to ensure that the relevant questions of the research are addressed by establishing a comfortable atmosphere within the group, paying careful attention to participant responses and body language, encouraging all participants to be a part of the discussion and managing the time(Krueger, 1994, Litoselliti, 2003, Krueger, 1998). In the present study, the whole discussion was carried out in a local language understandable to all the participants. There are five stages of data analysis in any focus group research including 1. Familiarisation of the data, 2. Identifying themes 3. Indexing all data in a textual form 4. Charting includes rearrangement of themes according to the thematic framework and 5. Mapping and interpretation (Pope et al., 2000).

There are some potential limitations in focus groups, mainly scope for bias and manipulation in the discussion, leading participants and influencing their responses. Often in a group, a dominant person can control the discussion, while others may remain silent and there is always a challenge in distinguishing between an individual view and a group view since individual behaviour is subject to group influence and vice versa. Also there is a great difficulty in making generalisations based on the focus group information due to the limited number of participants (Litoselliti, 2003).

For this research, the participants were selected from Prakasam district in the state of Andhra Pradesh mainly for two reasons. The prime reason was the existence of community eye care workers and vision centre activities in this district. The primary eye care service with the support of community eye care worker at the village level and a vision centre for a group of every 30 to 40 villages has been in place more than 8 years and the district has 30 fully functional vision centres and more than 35 field workers working at the community level. This model was considered adoptable by IAPB[2] for other regions in the country and internationally https://www.iapb.org/wp-content/uploads/Vision-Centre-Model-BP.pdf. The PEC team working in this district are attached to 3 secondary eye care centres and of which two centres

[2] International Agency for prevention of Blindness

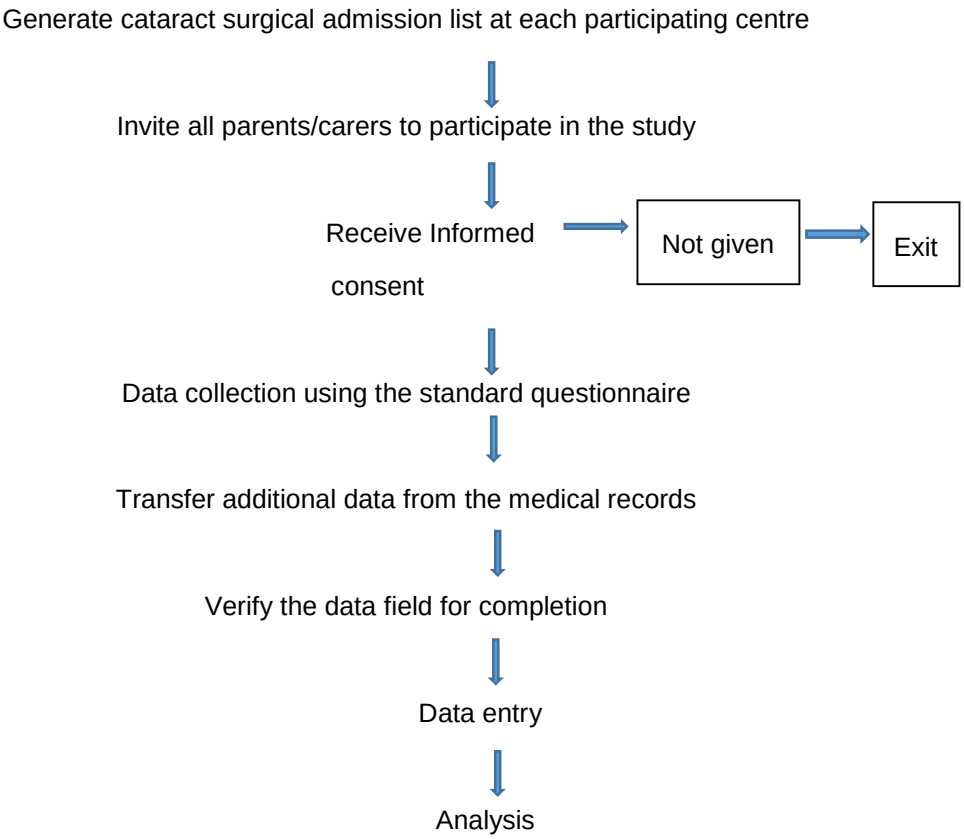
were selected using purposive random sampling and a set of 20 VTs in a group of 10 and 10 field workers were invited to participate in this discussion.

A research participant information sheet containing the purpose of this research (Appendix 2) was given to the invited participants and those who agreed to participate in the discussion signed individual informed consent forms before the discussion. After the discussion the audio tapes were transcribed and thematic analyses was carried out; the details of the analysis performed are explained in chapter 6.

2.7 Study enrolment process

The study subjects were recruited from the nine participating centres during the study period. Based on hospital appointment records, each parent/ carer of a child due to have cataract surgery was contacted in person at the hospital rooms where the child was admitted for surgery and the study interviewer extended the invitation to participate in the study by issuing the participant information sheet written in local language. Upon receiving the signed informed consent, a time for interview using a predesigned questionnaire was set according to the convenience of the carers' on any one of the three days that the child was admitted in the hospital for surgery. Figure 2.3 summarises the procedure followed for quantitative data collection.

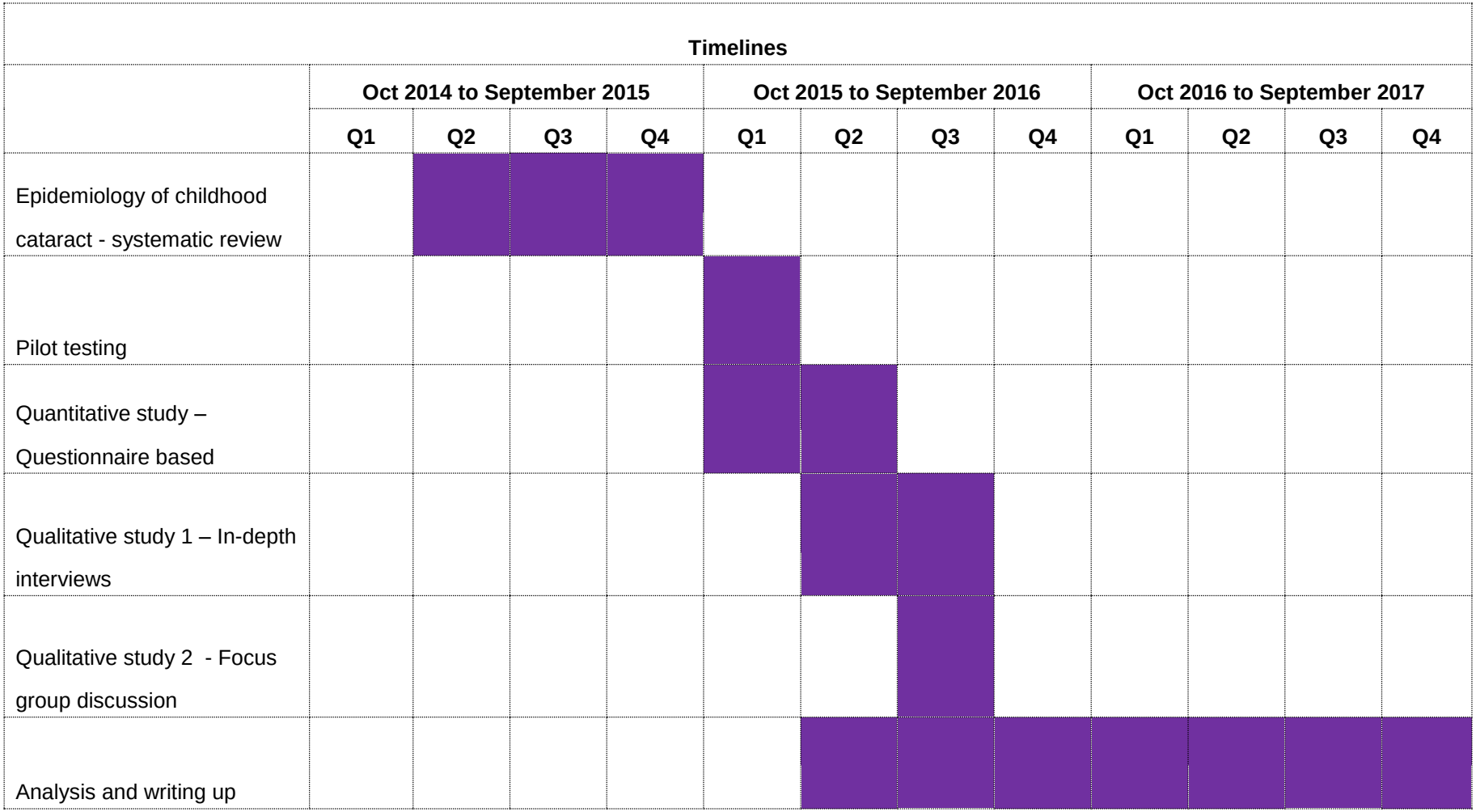
Figure 2.3 Flow chart of study process followed for quantitative data collection



2.8 Data collection plan

This research had four major data collection phases using different methodologies and Figure 2.4, the Gantt chart shows the timelines adopted for data collection.

Figure 2.4 Gantt chart of quantitative and qualitative components of study (October 2014 to September 2017)



2.9 Ethical considerations

Permission to conduct the study was received from the School of Health Sciences, City, University of London's Research Ethics committee (PhD/15-16/01). As this study involves data collection from international locations, individual permission from each of the nine participating hospitals' Institutional Review boards were obtained. The ethics approval letters are included in Appendix 1. The research involves accessing the medical records of the children undergoing cataract surgery in the participating hospitals and collecting related information about the children's eye health from their parents / carers. Considering the inability of the child to give consent, the informed consent was obtained from the parents / carers for this study.

The principles outlined by the Helsinki declaration on research on human developed for the medical community by the World Medical Association were followed (World Medical, 2013) including respect for human beings, research merit and integrity, privacy and confidentiality of personal information of research subjects.

Written Informed consent was gained from all the parents /carers of the child participants involved in the study. A study participant information leaflet was developed in English and translated into all 6 regional languages explaining the details about the study and was given to each potential participant prior to enrolment in the study. The conditions of consent included; consent should be a voluntary choice, should be based on sufficient information and adequate understanding of both the proposed research and the implication of participation. Mostly importantly, it was clearly stated that the participation or non-participation in this research will not alter the treatment that they were scheduled to receive from the hospital.

Qualitative research involves enquiry and investigation into people's lives, experiences and behaviours, the values and principles including importance and integrity, fairness and respect were maintained (Denzin N, 2000). The in-depth interviews were conducted at the hospital premises in a separate room with only the carers and their family present with the researcher for adequate privacy. Similarly, home interviews were also conducted when there were no persons other than the family members were present.
Individual consent forms were obtained from all the primary care providers (vision technicians and community eye care workers) participated in the Focus group discussion with an

emphasis given on audio recording the conversation and the discussions were organised at the hospital premises without any interruption from either the staff or the patients.

Access to the medical records was with permission from the respective authority and the records were not moved out of the hospital. All the data collected in the study was stored and maintained confidentially in a secured location and the raw data has been maintained for the period required by the ethics review committees.

2.10 Research collaboration

There are four equally important phases in any research study including the design, data collection, analysis/interpretation and dissemination. Considering the magnitude of the data collection involved in this study, collaboration was important for this research study. The L V Prasad Eye Institute and ORBIS International in India were established as two major collaborators.

Research partners:

Initially, this research was planned to collect data from the three hospitals located in Telangana and Andhra Pradesh where the LVPEI's tertiary centres are located. Later this research attracted the interests of Orbis International's India country program, as preventing childhood blindness was one of their priority areas in India. Considering the importance of this study and the value it would add in collecting data from multiple locations across India, the second collaboration with the Orbis was established for this research. The data collection centres were finalised with the support from these two major collaborators.

L V Prasad Eye Institute (LVPEI)

LVPEI (www.lvpei.org) was established in 1987, is a comprehensive eye health facility with its main campus located in Hyderabad, India. A World Health Organization Collaborating Centre for Prevention of Blindness, the Institute offers comprehensive patient care, sight enhancement and rehabilitation services and high-impact rural eye health programs. It also pursues cutting edge research and offers training in human resources for all levels of ophthalmic personnel. The LVPEI network comprises a 'Centre of Excellence' in Hyderabad, 3 tertiary centres in Bhubaneswar, Visakhapatnam and Vijayawada, 16 secondary and 144 primary care centres that cover the remotest rural areas in the four states of Telangana, Andhra Pradesh, Odisha and Karnataka. The Institute's innovative and comprehensive

approach to community eye health, the LVPEI Eye Health Pyramid, has been adopted as a model by the Government of India and by other developing countries. Through three decades since its existence, LVPEI has served over 21.3 million patients, with more than half the number of patients receiving services free of cost, regardless of the service complexity. The institute attracts patients from all over the country and internationally. Annually, LVPEI networks provides services to over 400,000 children as outpatients and 25,000 children receives surgical services.

For this research, three of the LVPEI centres located in Hyderabad, Vijayawada and Vishakhapatnam were included as data collection centres. The researcher worked with LVPEI in their community eye health division for the last ten years prior to this research, and during which time this research idea was conceived. The researchers' personal interaction within the local communities as part of the requirement of her work helped her to develop interest in exploring the issues contributing to the delayed access for cataract surgery in children from the rural areas. Through her experience of working with the institute, this collaboration was established to include three of the LVPEI centres for data collection for the purpose of this research. LVPEI has one more tertiary centre located in the state of Odisha which was not included in this study due to the various logistics inconvenience such as distance, language and budget constraints etc.

ORBIS International

ORBIS is a non-aligned, non-profit, global development organization whose mission is to preserve and restore sight by strengthening the capacity of local partners in their efforts to treat and prevent blindness. With its head office based in New York, it has affiliates in UK, Canada, France and Hong Kong. ORBIS's interventions are concentrated in the countries with a high incidence of avoidable blindness like India, China, Bangladesh, Ethiopia and Vietnam. In the year 1999, ORBIS has started its Liaison Office in New Delhi for India Country Programs. Capacity building and prevention of childhood blindness have been the major thrust of ORBIS in India. Currently, Orbis partners with 35 eye hospitals all over India in providing capacity building to reduce blindness and visual impairment in children. The six ORBIS (http://gbr.orbis.org/country/india/) partner organizations are regional eye centres providing speciality services including children's eye care were included as data collection centres for this research. These six centres are identified from the 35 ORBIS partner

organizations in India based on the volume of childhood cataract services rendered by the respective centres.

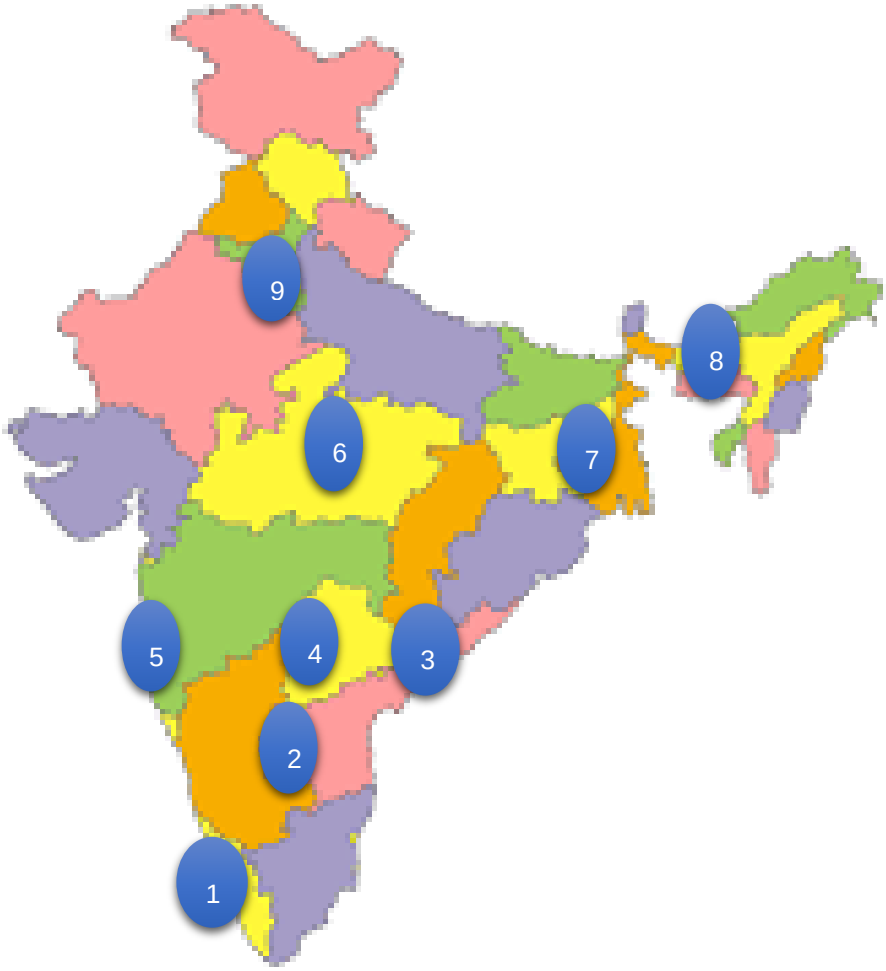
Data collection from different geographical locations was planned to explore various cultural and regional differences in the barriers to access childhood cataract services. Currently, there exists a huge variation in these regions in terms of health infrastructure, literacy levels and other social determinants of health.

2.11 Study Locations

The data collection was done in the following nine hospital located in 8 different states across India (4 to 9 are Orbis International supported partner centres):

1. Little Flower Hospital & Research Centre, Angamaly, Kerala
2. L V Prasad Eye Institute (LVPEI), Vijayawada, Andhra Pradesh, India
3. L V Prasad Eye Institute (LVPEI), Hyderabad, Telangana, India
4. L V Prasad Eye Institute (LVPEI), Visakhapatnam, Andhra Pradesh, India
5. PBMA's H V Desai Eye Hospital, Pune, Maharashtra, India
6. Sadguru Netra Chikitsalaya, Shri Sadguru Seva Sangh Trust, Chitrakoot, Uttar Pradesh
7. Vivekananda Mission Ashram, Netra Niramaya Niketan, Haldia, West Bengal, India
8. Sri Sankaradeva Nethralaya , Guwahati, Assam , India
9. Dr. Shroff's Charity Eye Hospital, Delhi, India

Figure 2.5 Map of India showing the study locations



Dr. Shroff's Charity Eye Hospital, http://www.sceh.net/ is located in Delhi, the country's capital city and has branches in Haryana, Uttar Pradesh and Rajasthan. This hospital was established in the year 1914 and attracts patients from most of North India. This hospital is located in main city of Delhi and has better transport connectivity to this centre. This centre has a dedicated Paediatric Ophthalmology unit through which the hospital provides services to over 120,000 children as outpatients and 800 children receives surgical services every year.

Pune Blind men association's (PBMA) H V Desai Eye Hospital, http://hvdeh.org/ located in Pune in the state of Maharashtra and has two branch hospitals in Maharashtra. This hospital was established in the year 2000 and has a dedicated Paediatric Ophthalmology unit and serves over 129, 000 children as outpatients and 450 children receives surgical services every year. This hospital is located outside the main city of Pune.

Sadguru Netra Chikitsalaya, Shri Sadguru Seva Sangh Trust, http://www.sadgurutrust.org located in Chitrakoot in the state of Uttar Pradesh and has a branch in the state of Madhya Pradesh. This hospital was established in the year 1968 and has a dedicated Paediatric Ophthalmology unit and serves over 135,000 children as outpatients and 2400 children receives surgical services every year. This hospital is located in a remote rural area. The village where this hospital is located is popular only for two things, one is this hospital and a famous pilgrimage centre which attracts people from all over the country.

Vivekananda Mission Ashram, Netra Niramaya Niketan, http://www.vmaindia.net located in Haldia, in the state of West Bengal and has another branch hospital in the state. This hospital was established in the year 1994 and has a dedicated Paediatric Ophthalmology unit and serves over 53,000 children as outpatients and 500 children receives surgical services every year. This hospital is located in a very remote village and serves as a main referral centre for paediatric eye care services for the eastern region.

Sri Sankaradeva Nethralaya, located in Guwahati, in the state of Assam. This hospital was established in the year 1995 and has a dedicated Paediatric Ophthalmology unit and serves over 40000 children as outpatients and 400 children receives surgical services every year. This is the only non-governmental hospital with paediatric eye care facility for the entire North Eastern region.

Little Flower Hospital & Research Centre, http://www.lfeyehospital.com/ located in Angamaly, in the state of Kerala. This hospital was established in the year 1964 and has a dedicated Paediatric Ophthalmology unit and serves over 83,500 children as outpatients and 1400 children receives surgical services every year.

Community outreach services for the children

All the nine hospitals participating in this research have a dedicated community eye care team. These teams are involved in planning, organising and implementing focused community screening programs for children both at the community level and at the schools. These programs were not limited to the surroundings of the hospitals, extending to the previously unreached community within their respective state and sometimes, in addition to neighbouring states. Any child who have accessed and identified for cataract or other surgical services during the community screening program mostly provided with free transport and surgical services. In general, community screening programs (mostly called as 'camps') are quite popular in India and these programs have wider reach within the communities.

The nine participating centres represent five regions based on their geographical location as given below:

Hospital Name	**Regional allocation**
L V Prasad Eye Institute (LVPEI), Hyderabad, Telangana, India L V Prasad Eye Institute (LVPEI), Visakhapatnam, Andhra Pradesh, India L V Prasad Eye Institute (LVPEI), Vijayawada, Andhra Pradesh, India Little Flower Hospital & Research Centre, Angamaly, Kerala	Southern region
PBMA's H V Desai Eye Hospital, Pune, Maharashtra, India	Western region
Sadguru Netra Chikitsalaya, Shri Sadguru Seva Sangh Trust, Chitrakoot, Madhya Pradesh, India	Central region
Dr. Shroff's Charity Eye Hospital, Delhi, India	Northern region
Vivekananda Mission Ashram, Netra Niramaya Niketan, Haldia, West Bengal, India Sri Sankaradeva Nethralaya , Guwahati, Assam , India	Eastern region

2.12 Analysis plan

The quantitative data were entered into an Excel database. Each variables were labelled independently to correspond with the questionnaire. The spreadsheet was pretested to ensure all variables were matched correctly. Data entry at each centre was verified with the medical records independently by the researcher before being collated for final analysis. All the quantitative analyses were performed using SPSS version 22. Descriptive statistics including proportions, means, standard deviations and T test were performed to determine the mean age differences across a number of socio demographic variables.

One way ANOVA test was used to calculate the variance within and across the regions for age at presentation for childhood cataract. Univariate and multivariate logistic regression analyses were performed to identify variables associated with early and late presentation for childhood cataract surgery. A p value <0.05 was considered statistically significant. The detailed analyses performed was explained in chapter 4, methods section.

Both in-depth interviews and focus group discussions were audio recorded and professionally transcribed in English. All the transcripts were analysed using NVivo version 11 software (http://www.qsrinternational.com/). The software was used to code transcripts so that conceptual relationships across different interviews could be identified, and key words could be counted. The software facilitated systematic, efficient coding and complex analyses.

The primary aim of identifying barriers and enablers both from the perspectives of parents and the primary eye care providers was to provide a basis for developing interventions to promote the uptake of childhood cataract services. The Theoretical Domain Framework (TDF) was designed for ease of use by researchers from a range of backgrounds, to identify barriers and enablers systematically and integrate these into behaviour change theories (Michie et al., 2005a). Given the non-psychology background of the researcher, this TDF approach was found appropriate for qualitative analysis to identify areas for developing an implementation plan for achieving positive health seeking behaviour in these communities.

In-depth interviews were coded using a theoretical domain framework (TDF) and themes were identified within each domain and interpreted further. The focus group discussions were analysed thematically using content coding and interpreted. Following this all the identified themes were mapped with the TDF domains for further planning. The main aim of using TDF

approach for analysing the in-depth interviews was to develop theory informed behaviour change interventions to address access issues to childhood cataract (French et al., 2012a). A detailed discussion on the analysis performed using in-depth interviews and focus group discussions were explained in Chapter 5 and Chapter 6 respectively.

2.13 Introducing the research field

India is the second-most populous country in the world with over 1.3 billion people and the fourth largest economy in the world (Hubacek et al., 2007) and India alone represents almost 17.31% of the world's population, which means one out of six people on this planet live in India. India is composed of 29 states and 7 union territories[3] (including a national capital territory).[4] India is a vast country with various diversity including physical features, race, religion, linguistic and political. Health care in India is provided by government, Non-governmental organisation and private hospitals and clinics.

In India, central and state government has an extensive network of both funded and managed health facilities which provides low cost preventive and curative health services for each state. A regular budget allocation both from central and state government goes for the management of public health facilities. However, the proportion of persons utilising the outpatient and hospitalisation services in public health facilities has declined considerably and even the government spending on health has consistently been low at around 1% of GDP (Shahrawat and Rao, 2012). Due to this, the out of pocket expenditure on health care has increased substantially over the years as at present almost 70% of the health care is provided by the private sector in India (Kumar and Roy, 2016). Related to this, it was estimated that between 32–39 million people are pushed into poverty every year due to health payments (Bhandari et al., 2010).

An additional issue is that the majority of the private providers accessed by the rural population are unqualified. Approximately 70% of rural residents and 31.5 % of urban residents seek health care from providers with minimal or no training (Das et al., 2012).

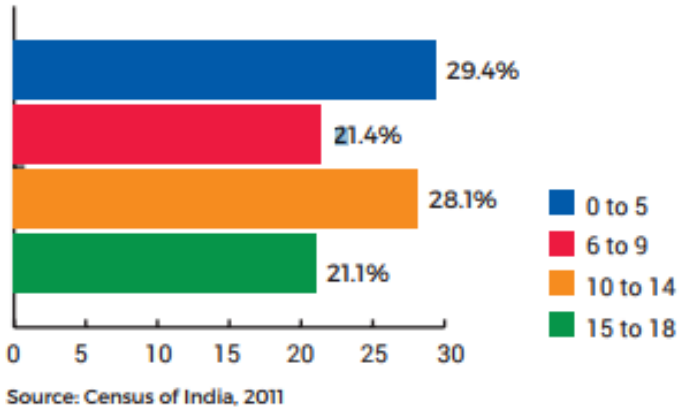
[3] The union territories are governed by administrators, appointed by the President of India.

[4] States and Union Territories of India - Source - Government of India Official Website

2.13.1 Children in India

India is home to the largest number of children in the world and around 19 per cent of the world's children live in India. A total of 472 million children (0–18 years) live in India comprising 39 per cent of the country's total population, out of which 247.5 million (52.4 %) are male and 224.6 million (47.6 %) are female. 138.9 million children (29.4 %) are in the 0–5 years age group, 100.9 million children (21.4 %) are in the 6–9 years age group, 132.7 million children (28.1 %) are in the 10–14 years age group and 99.7 million children (21.1 percent) are in the 15–18 years age group as shown in Figure 2.6.[5]

Figure 2.6 Children population in various age groups in India



2.13.2 Gender ratio

Gender imbalance has been an issue for the last few decades. In many parts of the country, there is a significantly lower number of girls compared to boys in their age group. Figure 2.7 shows the gender ratio in the year 1961 and 2011. In 1961, the gender ratio was equal in most regions except in a few places where more males per 1000 females was reported in the northern region of the country. In 50 years' time, there is a significant reduction in the number of girls per 1000 males in the northern area and the imbalance is similar in both urban and rural areas in 2011.

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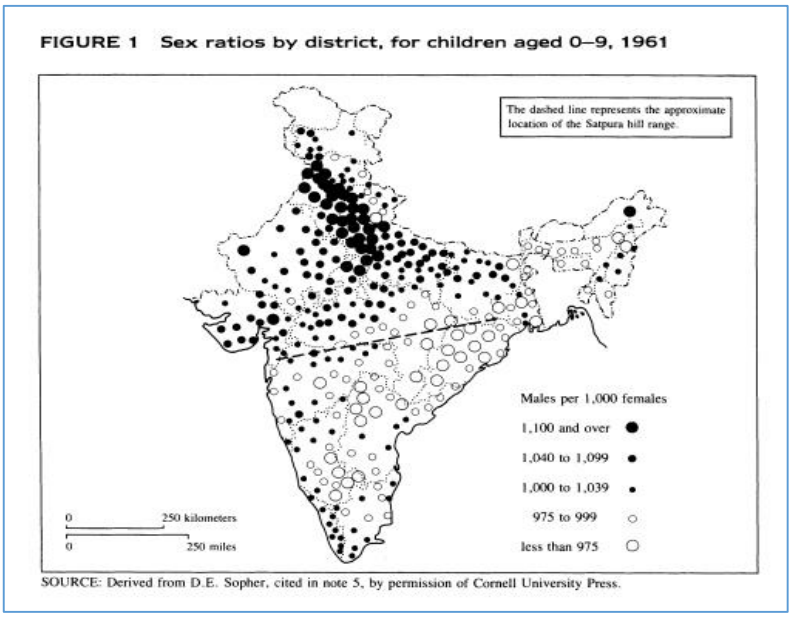
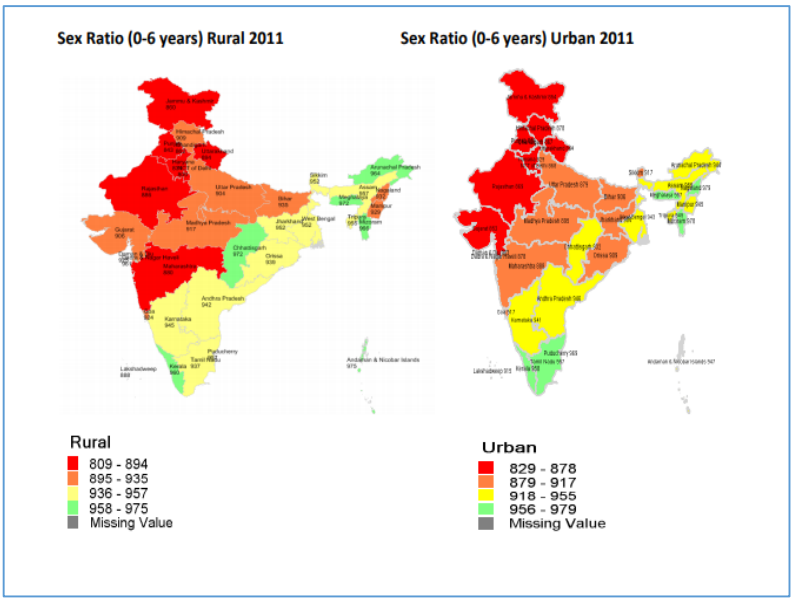
5 file:///U:/Main%20reports/Full%20text%20references/methods/Status_of_children_in_urban_India-Baseline_study_2016.pdf.

Figure 2.7 Gender ratio in the year 1961 and 2011

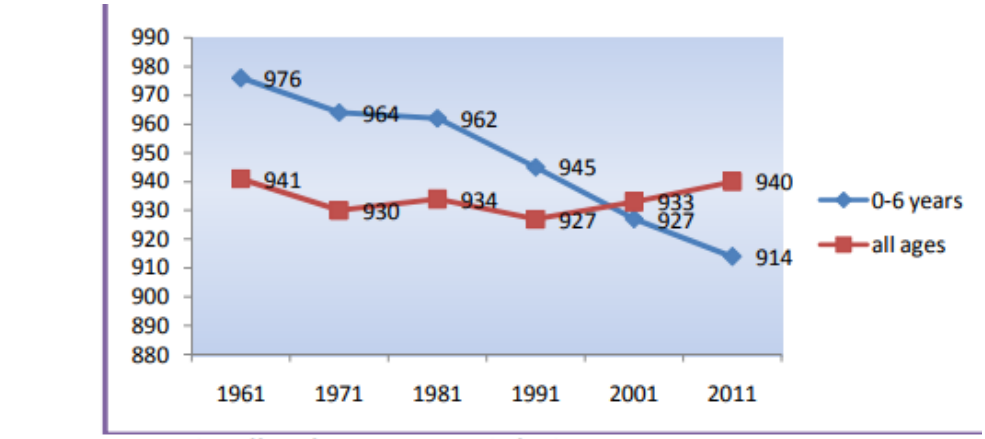




Source: Census, India, Office of registrar general of India

Each year, an estimated 26 million of children are born in India. It is significant that while an absolute increase of 181 million in the country's population has been recorded during the decade 2001-2011, there is a reduction of 5.05 million in the population of children aged 0-6 years during this period (see Figure 2.8). It was reported that the decadal decline in population was more for female children (3.8%) than male children (2.4%) in the age group 0-6 years (India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012)(India, 2012) http://mospi.nic.in/sites/default/files/publication_reports/Children_in_India_2012-rev.pdf .

Figure 2.8 Trends in child and overall sex ratio - India



Source: Census, India, Office of Registrar General of India

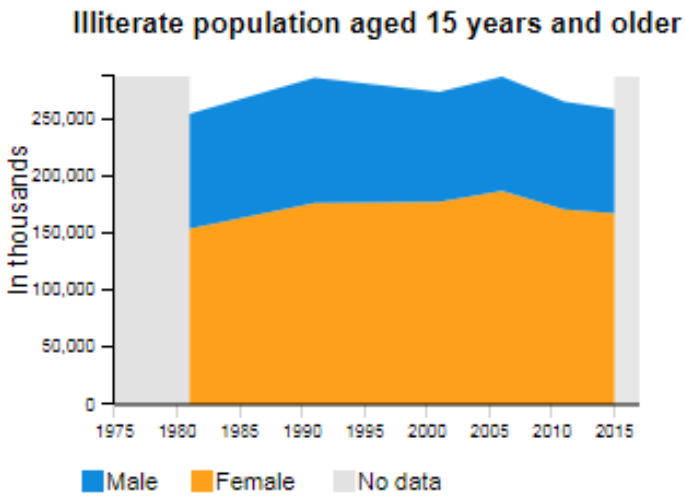
Life expectancy at birth is 63 years for boys and 66 years for girls, however the mortality rate for children younger than 5 years is 69 per 1000 live births in India. India is among the countries where child mortality rate is alarmingly high. Health status of any country is assessed by a few vital factors and Infant mortality rate (IMR) is considered as one of the most sensitive indicators of health status of a community Infant mortality rate is defined as the infant deaths (less than one year) per thousand live births. India's IMR was 72 per 1000 live births in 1996.

However, there is a wide variation among different states. IMR ranges from 13 in the state of Kerala to 97 for Madhya Pradesh (Anand et al., 2000). Gender disparities in health and education are higher in South Asia, including India, than anywhere else in the world (Claeson et al., 2000). For example, a girl in India is 30-50% more likely to die between her first and fifth birthdays than is a boy; thus, eliminating gender gaps in mortality rates would

significantly reduce infant and child mortality overall. One reason for gender differences in child mortality is a preference for sons (Arnold et al., 1998), and after the first month of life other factors come into play, including environmental and behavioural factors, such as care-seeking practices. Girls are often brought to health facilities in more advanced stages of illness than boys, are taken to less qualified doctors when they are ill, and less money is spent on medicines for them than for boys (Claeson et al., 2000).

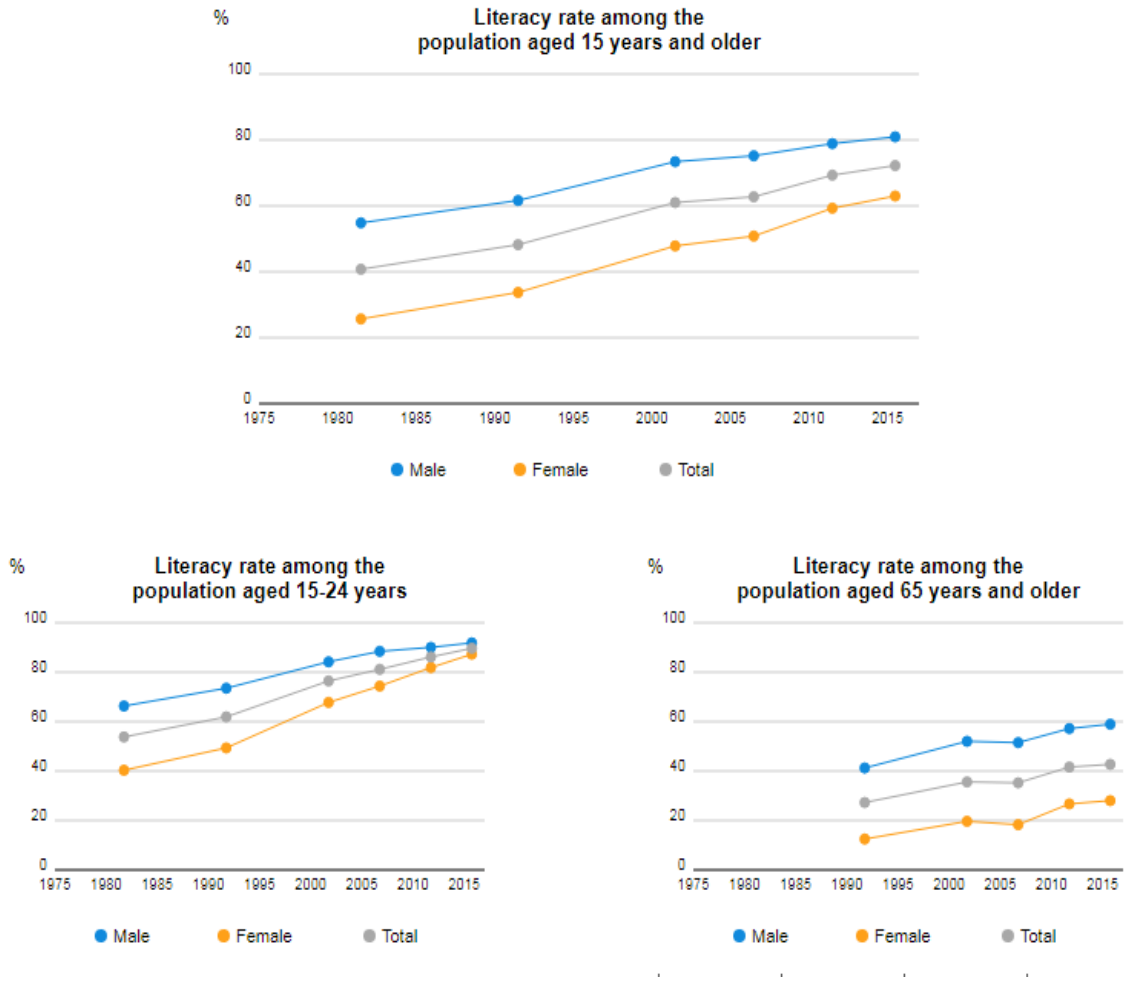
The child mortality is hugely varied between south and northern states in the country and the previous research attributed these regional differences to lower autonomy of women in the northern kinship system and suggested that 'even...in the absence of modern health education and services - differences in kinship structure and female autonomy between north and south may influence patterns of child care, and hence child mortality' lower in many southern states (Jain, 1985)

Figure 2.9 Number of children with no education by gender



In India, the primary school education begins at the age of 6 years and around 12% of the children go to pre-primary before 6 years. The pre-primary education is offered only in private sectors. For the primary education, the enrolment is almost 100% in both genders whereas the enrolment rate decreases gradually afterwards around 73% in secondary schools and only 25% of the total children enrolled for tertiary education. Figure 2.9 shows the number of children aged less 15 years who can't read and write, most of them are girls http://uis.unesco.org/en/country/in?theme=education-and-literacy .

Figure 2.10 Literacy rate among different age groups in India.



Overall there was an increase in the proportion of people getting educated and especially in the younger age group (15 – 24 years) the literacy rate among boys and girls are almost similar (see Figure 2.10).

Despite progress in Indian health sector, individuals with the greatest need for health care have the greatest difficulty in accessing health services and are least likely to have their health needs met. Substantial socioeconomic inequalities exist in access to health care in India. In 2005–06, national immunisation coverage was 44%, whereas the coverage was 64% for children of mothers with more than 5 years of education, and 26% for children of mothers with no education. Similarly, even though rates of delivery in institutions have increased with time, only 40% of women in India report giving birth in a health facility for their

previous birth in 2005–06, with women in the richest quintile six times more likely to deliver in an institution than those in the poorest quintile (Balarajan et al.).

The International Agency for prevention of Blindness (IAPB) reports confirms from the population-based surveys that the prevalence of blindness in children and under-five mortality rates correlate reasonably well. The children born with blindness or became blind in early childhood may not survive longer https://www.iapb.org/vision-2020/what-is-avoidable-blindness/childhood-blindness .

2.13.3 Eye care infrastructure in India

India became the first country to start its blindness prevention initiative in the year 1976 under the name of National Programme for Control of Blindness (NPCB) (Jose and Bachani, 1995) (http://npcb.nic.in/index.asp). This program is sponsored by the government of India with the goal to reduce the prevalence of blindness from 1.4% to 0.3%. The government works through the established health systems and with the existing Nongovernmental organisations (NGO) in the country. Through its blindness prevention initiative, the government provides subsidy to all the NGO hospitals for their surgical performance mainly in the area of adult cataract and spectacle delivery for school children. Under the regular five year plan a separate budget and targets were fixed by state wise and the implementation is carried out at the state level through a dedicated team. Majority of the government funding goes for subsidy to promote adult cataract surgical coverage. The blindness prevention initiatives are monitored at each state level and for the country. The main key indicators assessed are cataract surgical coverage and cataract continues to be the major cause for blindness in the country (Sommer et al., 2014). In the financial year 2016 – 2017, 6.4 million cataract surgeries have been performed in the country[6].

Burden of blindness

Globally, there is a changing trend in the prevalence of blindness and visual impairment (VI) and similar trend of decrease in the prevalence of blindness was also reflected in India over the past decade (Neena et al., 2008). The WHO report also showed a significant reduction in

[6] Source, NPCB annual achievements statistics for the year 2016 – 2017; Accessed from http://npcb.nic.in/index1.asp?linkid=93&langid=1

the number of the blind persons in India from 8.9 million in 1990 to 6.7 million in 2002 (Resnikoff et al., 2004). A recent report from the Global Burden of Diseases (GBD) vision loss expert group that in South Asia blindness decreased from 1.7% to 1.1% and Moderate severe visual impairment (MSVI) from 8.9% to 6.4% (Jonas et al., 2014).

In India, there are wide regional variations in the reported burden of visual impairment. The prevalence of visual impairment among >40 years across the country ranges from 14.3% to 42.1% (Gupta et al., 2015). Even though decreasing trend in blindness and VI was seen in India, the prevalence of blindness in India is much higher compared to other countries. This increased prevalence of blindness was due to the increase in life expectancy and consequently the elderly populations in India (Prakash, 2003). All the epidemiological studies in India consistently shows Cataract and refractive errors were the major causes of visual impairment and blindness. Other emerging causes are irreversible blindness due to diabetes and glaucoma.

Human resources and infrastructure for eye care in India

The Global Advisory Committee of Vision2020 recommends 1 ophthalmologist and 1 ophthalmic assistant per 50,000 population. A survey conducted in 2004 in the country reported that there was nearly 1 ophthalmologist per 100, 000 population but this availability had wide variations between states and between geographic locations (Murthy et al., 2004).

India has 24 states. More than half of the available ophthalmologists in the country practice in just 5 states and 81% of the ophthalmologist in 10 states. Thus, more than one-third of states are served by less than one-fifth of the available ophthalmologists. Most practising ophthalmologists are concentrated in the metropolises while rural areas had relatively poorer access to eye care facilities, and this factor may have been improved over the last 24 years (Kumar, 1993). Similar statistics are important for other ophthalmic cadres which is presently not available in the country. Also, there are no recent report on the human resource availability in the country and currently one survey being undertaken by the Vision 2020 India forum, which would highlight the changes in the human resources availability and the prevailing gaps http://www.vision2020india.org/ .

2.13.4 Paediatric eye care in India

In India, children suffer with both preventable and treatable causes of childhood blindness and hence any programs targeted at preventing childhood blindness should be based on comprehensive eye care service delivery including prevention, promotion, treatment and rehabilitation for irreversible conditions (Dandona et al., 1998b). Also, a research report published in 2007 suggests a declining trend in corneal blindness in children and that the focus has to be shifted more towards curative services (Gogate et al., 2007).

In order to provide comprehensive eye care to children a team of specially trained professionals at each level are essential. WHO suggests one paediatric ophthalmology service centre for a population of 10 million with at least one specialty trained or oriented ophthalmologist (WHO, 2002) and other supporting team. However, a few paediatric oriented eye care professionals are available in the country (Vijayalakshmi et al., 2004). In addition, paediatric ophthalmologists are not able to practice solely on paediatric cases unless attached to large eye hospitals where large numbers of paediatric cases are encountered. Hence, paediatric ophthalmologists may attend to ophthalmic problems in other age groups. At the same time, in many countries both developed (Spielmann, 2003, Nucci, 2004, Kowal, 2003) and developing (Santiago, 2005, Spierer, 2003) paediatric eye care services are delivered by the general ophthalmologist without any formal training in children eye care.

The first national survey implemented to document the status of paediatric eye care in India in the year 2005 and the results concluded that the paediatric eye care facility available in India was inadequate to provide the services in the country (Murthy et al., 2008). There are only 0.63 paediatric ophthalmology service units per 10 million population and these centres availability are not equally distributed across the country. This lack of infrastructure and in adequate trained human resources to deal with children eye problem in the country has been addressed to some extent in the country by ORBIS International, an international non-governmental organization, in collaboration with tertiary eye care institutes in India. ORBIS initiate the paediatric ophthalmology learning and training centre (POLTC) project to develop comprehensive paediatric eye care teams comprising of six personnel: An ophthalmologist, anaesthetist, optometrist, nurse, counsellor and outreach coordinator to offer comprehensive eye care services for the children (Murthy et al., 2010). Since 2000, ORBIS developed 32 children eye care facilities spread across the country (http://gbr.orbis.org/country/india) and presently working in 17 states.

School vision screening programs are initiated by the government and implemented throughout the country through the hospitals both government and NGOs and provides free spectacles to children identified with refractive errors and around 750, 000 spectacles were issued to the children in the financial year 2016 – 2017[7]. The coverage of children is very sporadic and there is no organized screening program for infants and children. Those with clinical problems are referred to hospitals (Thomas et al., 2005). Other than the spectacle delivery, there is no other data available including number of surgeries performed in children at any central location to assess the performances.

[7] Source, NPCB annual achievements statistics for the year 2016 – 2017; Accessed from http://npcb.nic.in/index1.asp?linkid=93&langid=1

Chapter 3

3 Systematic Review on Global prevalence of childhood cataract

Summary

This chapter begins with rationale for conducting this systematic review and the detail descriptions are discussed about the process involved from the development of search strategy to the interpretation of the findings. The results were analysed in many different ways to arrive at a meaningful conclusion.

3.1 Introduction

Cataract is opacity of the lens of the eye, which impedes the passage of light. While, most cataracts are age related, occasionally this condition occurs in children (Randall et al., 2010). Cataract in children may be congenital or acquired, (due to injury, inflammation or disease) unilateral or bilateral (Gralek et al., 2007) and in all cases is treatable. Cataract in children is broadly classified as congenital, developmental and traumatic cataract. The challenges in cataract classification are described more in Chapter 4.

Childhood cataract is estimated that 200 000 children worldwide are blind due to cataract, and that a further 20 000 – 40 000 children are born each year with congenital cataract (Foster et al., 1997). Globally the incidence of cataract in childhood has been reported as 1 – 15 in every 10 000 live births (Gilbert, 2003). As described in Chapter 1, cataract blindness in children presents a major problem to developing countries in terms of human morbidity, economic loss, and social burden (Wilson et al., 2003).

Studies conducted in schools for the blind have investigated the various causes of childhood blindness including cataract. Previous reports from West Africa, South India and Chile showed that lens abnormalities accounted for 15.5%, 7.4% and 9.2% of blindness in such schools (Gilbert et al., 1993). Similar studies conducted in Malawi, Kenya and Uganda found that blindness was caused by unoperated cataract in 13.1%, 9.1% and 27.6% of children respectively (Gilbert et al., 1995). In Ethiopia, unoperated cataract or aphakia accounted for

9.2% of blindness in schools for the blind (Kello and Gilbert, 2003). With significant reductions in some of the preventable causes of blindness such as Measles and vitamin A deficiency, cataract has become the greatest cause of treatable blindness in children in developing countries (Waddell, 1998).

Reliable region-specific data on the prevalence and incidence of childhood cataract is important as part of the basis for policy decisions including the evidence-based allocation of resources. Cost and logistics limit the feasibility of the large scale data gathering required for prevalence estimates. The key informant method was introduced in an attempt to facilitate prevalence estimation, but a few studies have used this method to date (Muhit et al., 2007b, Muhit, 2007).

There is little epidemiological information about cataract in children globally and thus a lack of evidence to guide policy related to childhood cataract. Systematic reviews and meta-analyses are indispensable components in the chain of scientific information and key tools for evidence-based policy and practice. The highest level of evidence is provided by a systematic review. Prior to this work, there were no systematic reviews on the question of prevalence and incidence of childhood cataract globally.

3.2 Objectives

The aim of this study was to systematically review the existing research to determine a reliable estimate of global prevalence and incidence of congenital (from birth) and acquired (due to trauma or disease) cataract in children globally.

3.3 Methods

Search methods for identification of studies:

Cochrane library, Medline and Embase were searched (the date of last search was January 2015). The publications were searched through OVID database that provide access to online publications in the area of health sciences and through EBSCOHOST which provides access to range of library referencing services. The detailed search was performed using the search terms shown below.

OR (any of the following terms)	OR (any of the following terms)	OR (any of the following terms)	AND (a combination of one or more terms from the OR columns)
Child*	cataract	prevalence	
infan*	lens*	incidence	
p?ediatric*	near opacity*	epidemiology	
adolescen*			
teenage*			
juvenile*			
minor			
young people			

No restrictions were imposed based on language or year of publication. Bibliographies of related articles were checked to identify additional potentially relevant reports. Medline and Embase databases were searched for grey literature such as conference abstracts. The World Health Organisation website was searched for program reports and government documentation. The methodology of this review protocol has been registered and published on the Prospero database (reference number CRD42014014909).

3.3.1 Inclusion and Exclusion criteria

All studies published from any global location which estimated the prevalence and or incidence of cataract among children (aged less than 18 years) were considered for this review. In this context, prevalence indicates (Chap T Le, 1995) the number of children in a population that have cataract at a given point of time divided by those at risk (the total number of children in the population). Incidence indicates (Chap T Le, 1995) how many new cases of cataract occur in children under 18 within a defined period of time. For estimating prevalence, data from non-random samples (e.g. from schools for the blind) or based on self-report were excluded. For incidence studies, no exclusion criteria were imposed.

3.3.2 Data Abstraction and Quality Assessment

The review process consisted of the following five stages:

Stage1: The principal investigator conducted the detailed search using the search criteria outlined above and identified all the articles for this review. All the identified studies were organised in an excel sheet (both title and abstract) and shared with a second reviewer for an

independent screening. Efforts were taken to collect the abstracts for all identified articles and in case of missing abstracts the full text was used at the screening stage. Twenty eight studies including (16 in English, 5 in Chinese, 2 in German and 1 each in Polish, Spanish, Hungary, French and Turkish) were not included into the next stage due to non-availability of abstract or full text. Of these majority of them were conference abstracts.

Stage2: All of the studies derived from the search were independently assessed by two reviewers including the present author for inclusion based on title and abstract content, using the inclusion criteria outlined above. The two reviewers rated each identified article as "considered", "Rejected" or in a few cases, as "Unsure". Any discrepancies were discussed and resolved by consensus. If it was not possible to arrive at mutual consensus it was agreed to discuss with a third reviewer but the situation never arose in this review.

Stage 3: All of the studies considered for inclusion were assessed for methodological quality based on the full published paper. This step was very critical to assess the validity of the results of the included studies. In case of prevalence studies the methods adopted to estimate the results becomes an important aspect of considering the results of the study. The most important factors were the study samples and the objectivity and reliability of the measurements. For example, it was necessary to evaluate how the samples were selected to ensure the sample selected was representative of the population studied, whether adequate sample was included and appropriate sampling technique was applied to minimise the selection biases. Another most important aspect was the definition used for the condition and the objective technique used to assess the condition. These factors are very critical to consider the results of the studies for meta-analysis or synthesis of published evidence. If any non-objective measures were used to estimate the problem, it can lead to either over or under estimate of the overall prevalence of the condition studied.

The critical appraisal tool developed by Munn and his team (Munn et al., 2014) for the prevalence studies was considered for quality assessment. This instrument addresses validity of the included studies based on ten factors which can be grouped under three major headings as given below:

Description of factors included in quality assessment of prevalence studies

Factors	Description
Study subjects	Sample representation Appropriate subject selection Adequacy of sample size Clear description of study subjects and setting
Assessment	Objectivity of the condition measured Reliability of the assessment Appropriate data analysis Adequate sample coverage
Associations	Adjustment of all variations and Confounders Sub group analysis

This critical appraisal instrument tool was adopted and the assessment was conducted independently by two reviewers using this template (see Table 3.1).

Table 3.1 Critical appraisal template used for quality assessment of the studies in this review

Critical appraisal checklist for studies reporting prevalence data **Reviewer:…… ……..Date: ……..** **Author……. Year ……Record Number……**					
	Methodological criteria	Yes	No	Unclear	Not applicable
1	Was the sample representative of the target population?				
2	Were study participants recruited in an appropriate way?				
3	Was the sample size adequate?				
4	Were the study subjects and setting described in detail?				
5	Is the data analysis conducted with sufficient coverage of the identified sample?				
6	Were objective, standard criteria used for measurement of the condition?				
7	Was the condition measured reliably?				
8	Was there appropriate statistical analysis?				
9	Are all important confounding factors/ subgroups/differences identified and accounted for?				
10	Were sub populations identified using objective criteria?				
Overall appraisal:		Exclude ☐		Seek further information ☐	

For each factor, each reviewer answered the question with Yes, No or Not Applicable/Unsure. Any discrepancies in the quality assessment between the reviewers were discussed to reach consensus.

Overall, each study included in the systematic review was also included in the meta-analysis if it met the quality assessment criteria explained on page 79 (description of factors included in the quality assessment). This approach aligns with the Weight of Evidence framework to inform decision making (Gough, 2004).

The results of the quality assessment of the included studies are presented in Figure 3.1. Of the total 42 studies, twenty of them were excluded due to inadequate data or review studies or non-population based studies.

Stage 4: Based on the proposed outcome measures and to summarise the characteristics of the included studies, a data extraction template was developed. Data from first few included studies were extracted as a pilot to ensure all relevant information are captured. This pilot testing exercise was conducted by the principal investigator and amendments were carried out during the data extraction stage independently by two reviewers. Data were independently extracted from eligible studies by two reviewers using the template, and the resulting data were verified by a third reviewer. The extracted information includes: authors, publication year, journal, study design, geographical location, setting (community vs hospital), study population and participant demographics (including age, gender and socio economic status), cataract diagnosis (congenital or acquired), method of disease ascertainment, (either through vision screening or through assessment for visual impairment and blindness), incidence and/or prevalence data with 95% confidence intervals if available.

Stage 5: Final Quantitative data synthesis was carried out using MetaXL, in Microsoft office (Barendregt et al., 2013) and Open Meta Analyst software.

3.3.3 Statistical methods

Both meta-analysis and meta-synthesis were attempted and the results of each are reported. In the meta-analysis, an overall estimate of the prevalence and incidence across included studies was obtained, after stabilising the variance of individual studies with the use of Freeman- Tukey double arcsine transformation (Barendregt et al., 2013). The arcsine

transformation was applied to normalise the variance between the studies as we expected a high degree of heterogeneity among the included studies in the design and outcome measures. Heterogeneity was assessed using the χ^2 test on Cochrane's Q statistic and quantified by calculating the I^2 (Higgins and Thompson, 2002).

Heterogeneity was assessed using random – effects model and also examined by visually assessed across all studies the heterogeneity of all the studies in the review by reviewing the characteristics of the included studies and by looking for overlap of confidence intervals in the forest plot. The I^2 statistic describes the percentage of total variation between studies that is due to heterogeneity rather than chance. Negative values of I^2 are considered to be zero so that I^2 lies between 0% and 100%. A value of 0% indicates no heterogeneity and larger values indicates increasing levels of heterogeneity (Higgins et al., 2003). Since a high degree of heterogeneity was found in the included studies, the results were summarised and both median and prevalence ranges reported.

Global prevalence of childhood cataract was determined as well as prevalence according to the country's economic status. Countries' income status levels are defined according to their Gross National Income (GNI) per capita per year and it is calculated using the *World Bank Atlas* method (Randall et al., 2009), Countries with a GNI of US$ 1, 045 or less are defined as having low income economies; middle-income economies are those with a GNI per capita of more than $1,045 but less than $12,736; high-income economies are those with a GNI per capita of $12,736 or more. Lower-middle-income and upper-middle-income economies are separated at a GNI per capita of $4,125.

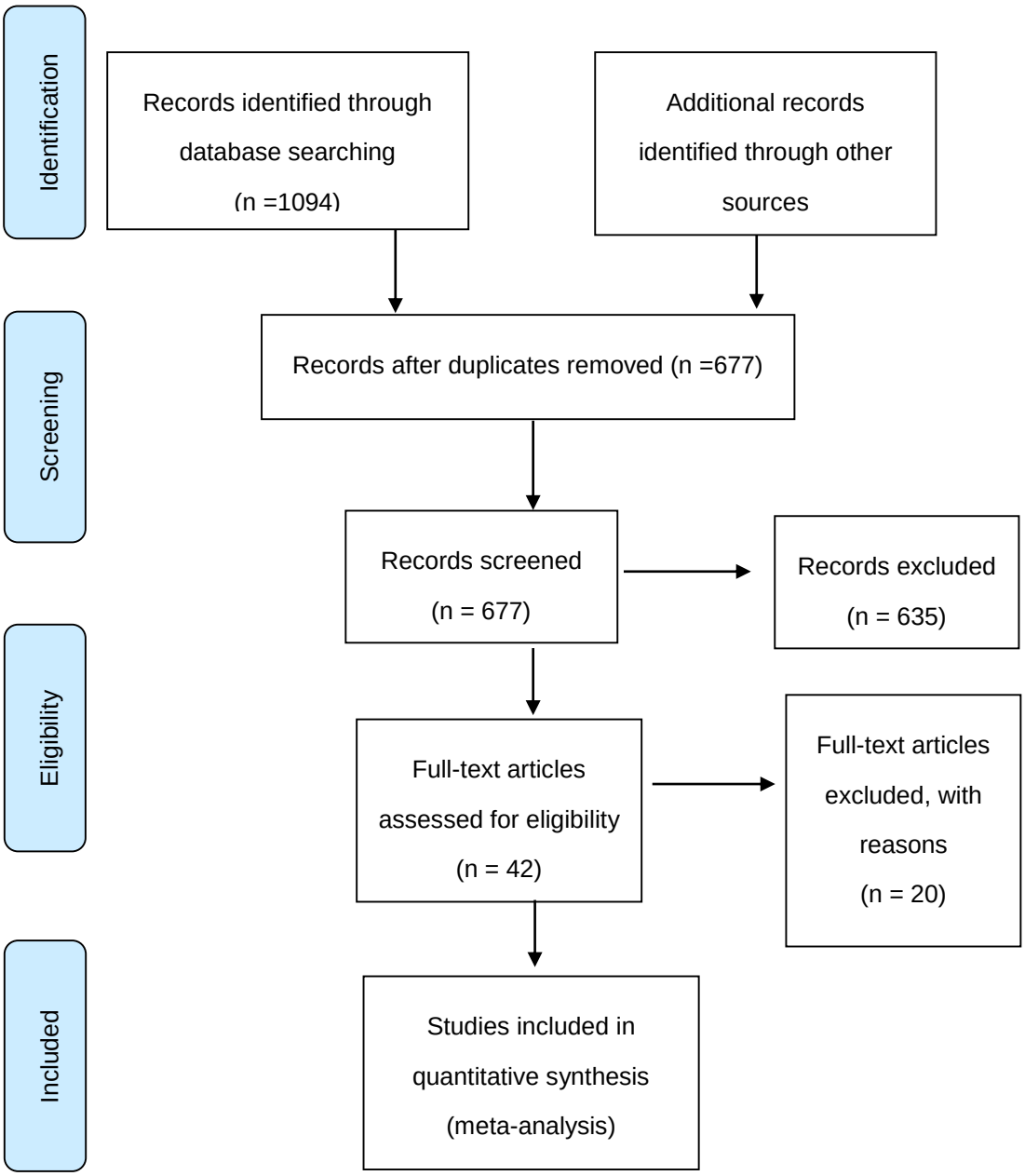
Another sub group analysis was performed to calculate the prevalence of childhood cataract, based on studies grouped according to geographical regions wise including North America, Europe & Central Asia, East & Asia Pacific, Sub Saharan Africa and South Asia for regional extrapolation.

3.4 Results

Review process flow

Out of a total of 677 potentially relevant titles/ abstracts, 42 full text articles were obtained, with 22 of these meeting the inclusion criteria. The review strategy is summarised in Figure 3.1.

Figure 3.1 Summary of review strategy - PRISMA Flow Diagram



3.4.1 Study Characteristics and Methodological quality

A majority of the studies reviewed were in English (n=39), two in Mandarin and one in Portuguese. Twenty two studies that reported prevalence or incidence of childhood cataract were identified and included in the final stage of data extraction. The exclusions were based on the study design and data availability and were not based on the quality of the published study. Specifically, population based prevalence studies including cataract data were included. Studies conducted in hospitals, schools or on specific populations such as war zone areas were excluded. Reasons for exclusion of the other 20 studies are reported in Table 3.2.

Table 3.2 Characteristics of the excluded studies after the methodological quality review of full text

S. No	Study	Reasons for exclusion
1	(Halilbašić et al., 2014)	Retrospective hospital based analysis of medical records and not a population based estimation of prevalence or incidence study
2	(Loewer-Sieger, 1975)	Not a population based study and the recruitment was based on special schools for the visually handicapped children
3	(Foster and Gilbert, 2003)	Review article on cataract in children and reported the estimate proportion of blind caused by cataract but not enough data to include in this review.
4	(Gilbert and Foster, 2001a)	Review of blindness in children, no data available. Bibliography was checked for additional studies.
5	(Alborz, 2013)	Estimating birth defects post war and there was no data reported on cataract in children
6	(Dandona and Dandona, 2003)	Population based study, however there was not enough data on cataract in children
7	(Rudanko and Laatikainen, 2004)	Not a population based study and the subjects recruitment was based on visual impairment registry
8	(Gilbert and Muhit, 2012b)	Review article, but there was no data on cataract reported
9	(Repka et al., 2012)	No data available on cataract in children

10	(Day et al., 1995)	Recruitment from high risk population exposed to nuclear reactor
11	(Shaikh and Aziz, 2005)	Population based study, but there was no data on congenital cataract although there was a report on traumatic cataract in children.
12	(Rodrigues et al., 2012)	Prevalence of cataract reported based on children attending the maternity clinics and GP centres.
13	(Kohler and Stigmar, 1973)	No data on cataract reported specifically
14	(Robaei et al., 2005)	Insufficient sample to identify cataract.
15	(Jensen and Goldschmidt, 1986)	School based study and there was no report on prevalence of cataract
16	(Robaei et al., 2006)	Based on children enrolled in schools
17	(Mousa and Suha, 2014)	The subject recruitment was based on clinic attendance
18	(Stayte et al., 1993)	Not a prevalence study
19	(Wedner et al., 2000)	Subjects recruitment was based on children enrolled in primary schools
20	(Hu, 1989)	No information reported on cataract

The included studies represented five geographical regions (Table 3.3) including Europe & Central Asia (n=8) (Abrahamsson et al., 1999, Bermejo and Martinez-Frias, 1998, Haargaard et al., 2004, Luteijn et al., 2014, Rahi et al., 2001a, Rahi et al., 2001b, Stewart-Brown and Haslum, 1988, Stoll et al., 1992), South Asia (n=8) (Dandona et al., 1998c, Dorairaj et al., 2008a, Fu et al., 2004, Limburg et al., 2012, Lu et al., 2009, Nirmalan et al., 2003, Pi et al., 2012, Xiao et al., 2011), East Asia & Pacific (n=2) (Cama et al., 2010, Wirth et al., 2002), Sub Saharan Africa (n=2) (Demissie and Solomon, 2011, Duke et al., 2013) and North America (n=2) (Holmes et al., 2003, SanGiovanni et al., 2002) (see Figure 3.2).

Half of the included studies (n=11) were published between 2004 and 2014 and all the included studies were published between 1988 and 2014. Eighteen studies reported data on

prevalence (Bermejo and Martinez-Frias, 1998, Cama et al., 2010, Dandona et al., 1998c, Demissie and Solomon, 2011, Dorairaj et al., 2008a, Duke et al., 2013, Fu et al., 2004, Holmes et al., 2003, Limburg et al., 2012, Lu et al., 2009, Luteijn et al., 2014, Nirmalan et al., 2003, Pi et al., 2012, Rahi et al., 2001a, SanGiovanni et al., 2002, Stewart-Brown and Haslum, 1988, Stoll et al., 1992, Xiao et al., 2011) and four studies reported incidence (Abrahamsson et al., 1999, Haargaard et al., 2004, Rahi et al., 2001b, Wirth et al., 2002). Sample sizes included in the studies varied greatly ranging from 3079 to 2.6 million children. Similarly, study designs, sampling strategy and study settings varied between the studies and the characteristics of the included studies are presented in Table 3.4.

Figure 3.2 Map showing the geographical distribution of included studies

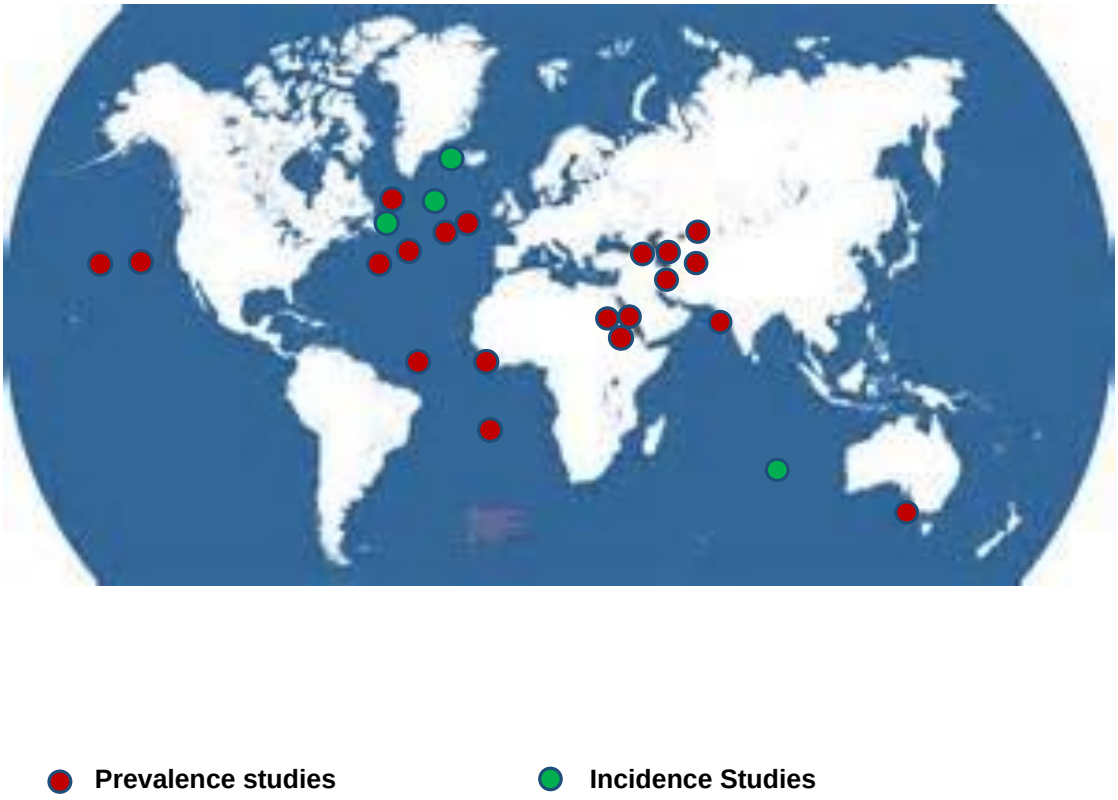


Table 3.3 Regional and Economic grouping of studies included in the review

Study	Country	Regional grouping	Economic grouping
Stewart-Brown 1988	UK	Europe & Central Asia	High Income economies
Stoll 1997	France		
Bermejo 1998	Spain		
Abrahamson 1999	Sweden		
Rahi 2001a	UK		
Rahi 2001b	UK		
SanGiovanni 2002	US	North America	
Holmes 2003	US		
Wirth 2002	Australia	East Asia& Pacific	
Haargaard 2004	Denmark	Europe & Central Asia	
Luteijn 2014	Europe		
Fu 2004	China	East Asia& Pacific	Upper Middle income economies
Lu 2009	China		
Cama 2010	Fiji		
Xiao 2011	China		
Pi 2012	China		
Li 2013	China		
Dandona 1995	India	South Asia	Lower middle income economies
Nirmalan 2003	India		
Dorairaj 2008	India		
Limburg 2012	Vietnam	East Asia& Pacific	
Duke 2013	Nigeria	Sub Saharan Africa	
Shirima 2009	Tanzania	Sub Saharan Africa	Low income economies
Demissie 2011	Ethiopia		

Table 3.4 Summary characteristics of the studies included for meta-analysis.

Authors	Country	Study period	Design	Sampling	Setting	Method of assessing V/A*	Age group (Years)	No of samples	Total no of cataract
Prevalence									
Stewart-Brown et al. 1988	UK	1980	Cohort	All children born during the study period	Hospital	Letters	10	12,853	7
Dandona et al. 1998	India	1996	Door to door enumeration	All children in the targeted area	Population	Not stated	0-15	113,514	9
Stoll et al. 1997	France	1979 -1994	Retrospective review of a surveillance system	All cases born during the study period	Hospital	Not stated	At birth	212,479	58
Bermejo et al. 1998	Spain	1980 -1995	Case control	All cases	Hospital based surveillance system	Not stated	At birth	1,124,654	71

Rahi et al. 2001a	UK	1995 -1996	Prospective surveillance	Screening	Hospital	Not stated	0 – 1	648,138	149
SanGiovanni et al. 2002	US	1959 -1965	Prospective longitudinal	All children born during the study period	Hospital and population	Not stated	0-7	53,724	73
Holmes et al. 2003	US	1978 – 1997	Retrospective review of medical records	All cases diagnosed during the target period	Hospital	Not stated	0-17	33,021	15
Nirmalan et al. 2003	India	2002	Cross sectional	Cluster sampling	Population	matching cards, <2 years target fixation	0-15	10,605	9
Fu et al. 2004	China	2001	Cross sectional	Cluster sampling	Population	letters, <3 years target fixation	0-6 years	60,124	9
Dorairaj et al. 2008	India	NA	Cross sectional	All children in the targeted area	Population	E, pictures, fix and follow	0-15	8684	6
Lu et al. 2009	China	2004	Cross sectional	Cluster	Population	Symbols and E	3 to 6	17,699	3

Cama et al. 2010	Fiji	2006 -2007	Population based retrospective review	All cases identified through the sources considered	Hospital and population	Pictures. Letters in school screening; unknown for other sources	0-15	98, 844	9
Demissie et al. 2011	Ethiopia	2009	Key informant method	All children in the targeted area	Population	Letters	0-15	58,480	12
Xiao et al. 2011	China	2009	Key informant method	All children in the targeted area	Population	Letters, pictures, toys	0-15	27,000	2
Limburg et al. 2012	Vietnam	2007	Part of RAAB survey	Cluster sampling	Population and schools	Letters, pictures, fix and follow or light perception	0-15	28,800	3
Pi et al. 2012	China	2006 -2007	Cross sectional	All children in the targeted area	Population	Letters	6 to 15	3,079	7

Duke et al. 2013	Nigeria	NA	Key informant method	All children in the targeted area	Population and schools	Letters, pictures, fixation.	0-15	1,160,000	38
Luteijn et al. 2014	Europe	2000 - 2009	Retrospective review of Population based surveillance system	All children registered during the review	Hospital	Not stated	At birth	3,295,000	418
Incidence									
Abrahamson et al. 1999	Sweden	1980 - 1997	Retrospective review of medical records	All children born during the study period	Hospital	Not stated	At birth	419,209	142
Rahi et al. 2001b	UK	1995 - 1996	Prospective surveillance	All cases during the study period	Hospital based active surveillance system	Not stated	At birth	735,000	248

Wirth et al. 2002	Australia	NA	Retrospective review of medical records	All cases during the study period	Hospital	Not stated	0-17	1,875,000	421
Haargaard et al. 2004	Denmark	1962 – 2000	Cohort	All children born during the study period	Population based using civil registration system	Not stated	0-17	2,616,439	1311

(* V/A – Visual Acuity)

Five studies were cross sectional (Dorairaj et al., 2008a, Fu et al., 2004, Lu et al., 2009, Nirmalan et al., 2003, Pi et al., 2012), six were retrospective based on medical records or a surveillance system (Abrahamsson et al., 1999, Cama et al., 2010, Holmes et al., 2003, Luteijn et al., 2014, Stoll et al., 1992, Wirth et al., 2002), three were based on prospective surveillance or longitudinal (Rahi et al., 2001a, Rahi et al., 2001b, SanGiovanni et al., 2002), three used key informant methods (Demissie and Solomon, 2011, Duke et al., 2013, Xiao et al., 2011), two were cohort studies (Haargaard et al., 2004, Stewart-Brown and Haslum, 1988) one used the Rapid Assessment of Avoidable Blindness (RAAB) method (Limburg et al., 2012), one was a case control study (Bermejo and Martinez-Frias, 1998) and one used door to door enumeration (Dandona et al., 1998c). Figure 3.3 summarises the results of the quality assessment for the 22 included studies.

As described earlier in the methods, of the three section, most studies met the criteria relating to study samples. The main drawback on the included studies include the assessment criteria. Many different method of assessments were adopted and except one study, other included studies did not meet this assessment criteria

Figure 3.3 Results of the quality assessment of the 22 included studies

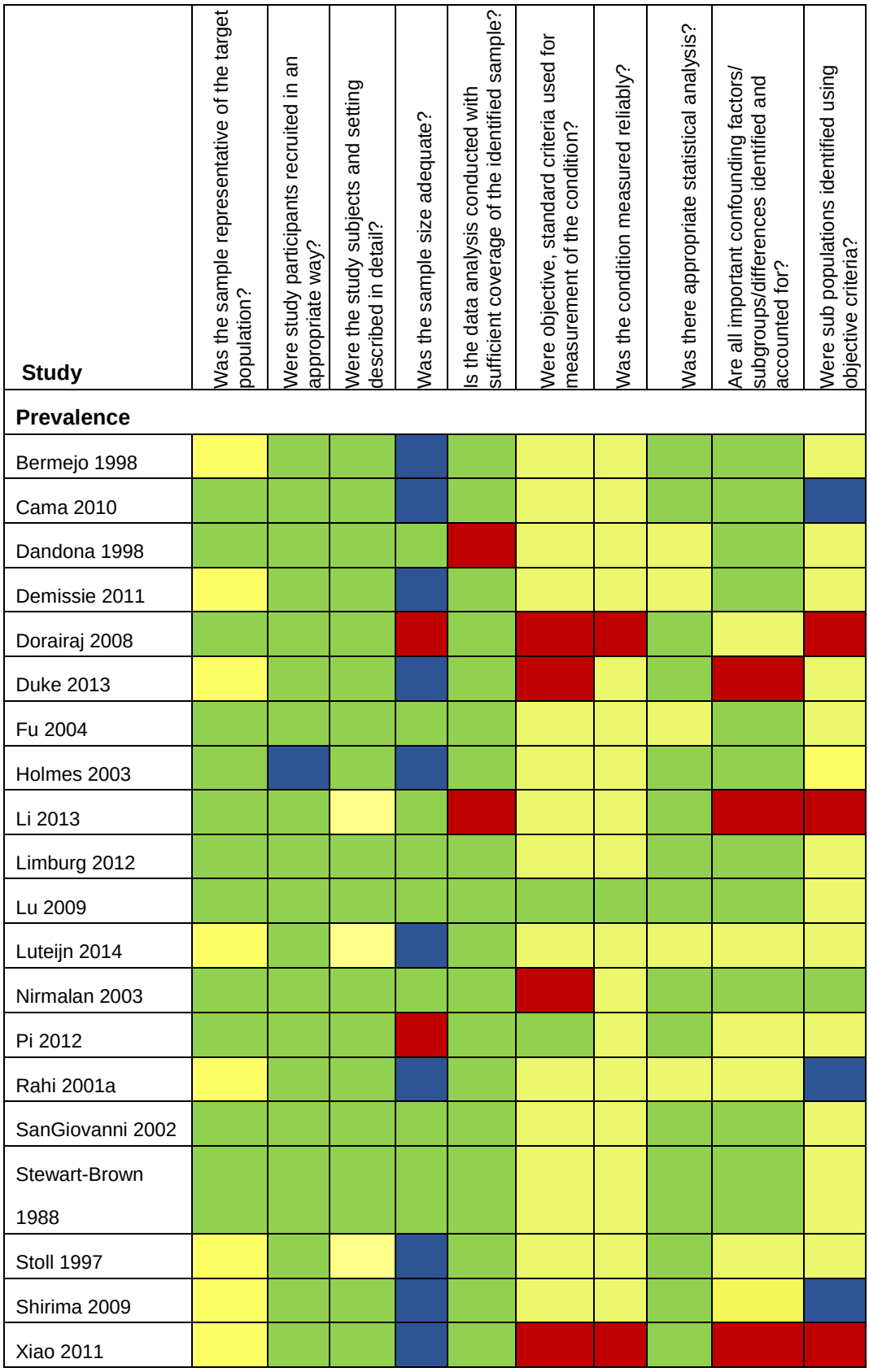
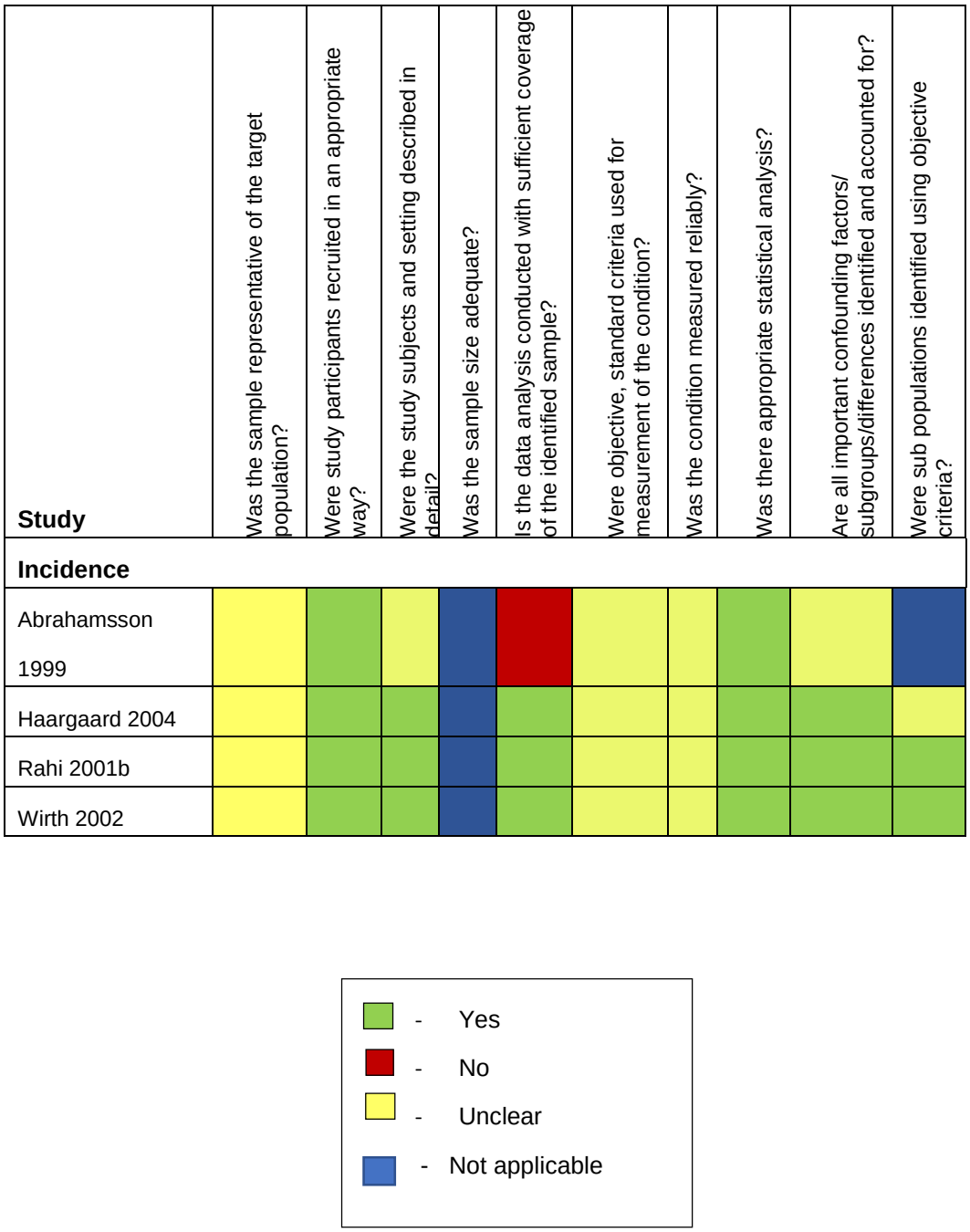


Figure 3.3 Results of the quality assessment of the 22 included studies



3.4.2 Quantitative data synthesis

A high degree of heterogeneity was found between the 18 prevalence studies (Cochran's Q test, $p<0.01$; I^2 =96%; see Figure 3.5). The overall prevalence of childhood cataract was estimated to be 1.14/10000 (95% CI: 1.06 – 1.22) (Figure 3.5) and prevalence in low and lower middle income economies was 0.46/10000 (95% CI: 0.36 - 0.59); in upper middle income economies it was 1.3 /10000 (95%CI: 0.85 – 1.85); in high income economies it was 1.35/10000 (95% CI: 1.25 – 1.45) see Figure 3.6. Each line in the figure represents a study and the mid-point on each line represents the effect estimate and the weight given to each study.

When calculating the pooled estimate, individual weightage was given to each study to describe the level of contribution of each study data which is indicated by the weight (size) of the box. More weightage was given to studies with greater sample size and smaller confidence intervals, which is indicated by a larger sized box and those studies had more influence on the pooled result.

The width of the line represents the confidence intervals (CI) for effect estimate for the study. The diamond shape below the studies represents the overall effect.

Figure 3.4 Forest plot on Global prevalence of Childhood Cataract

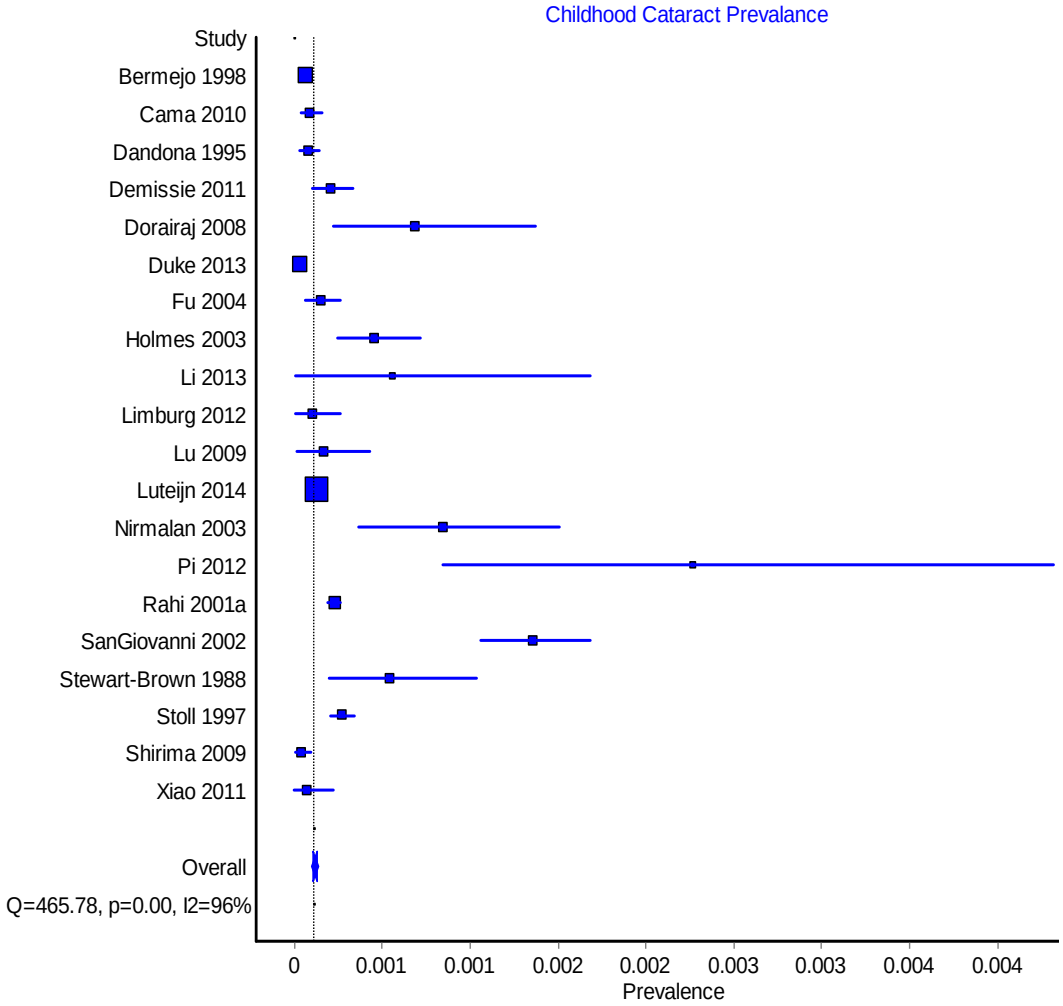
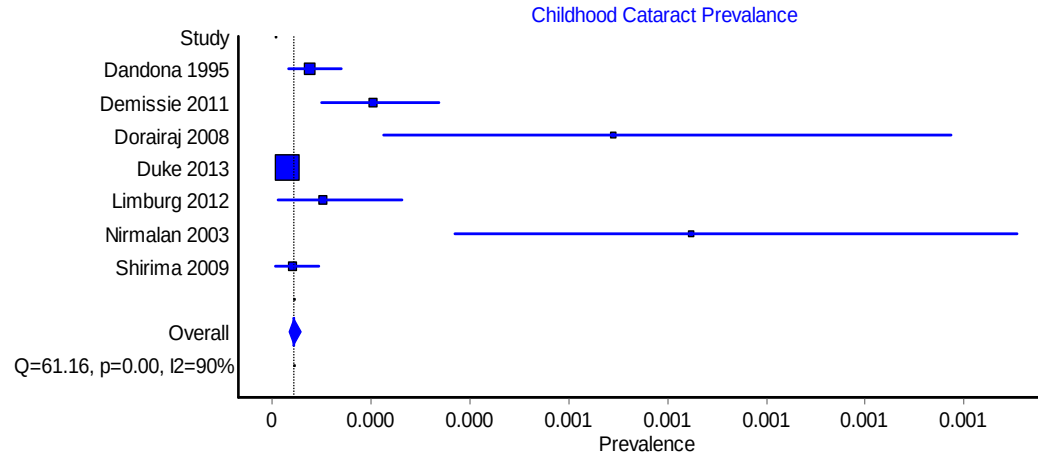
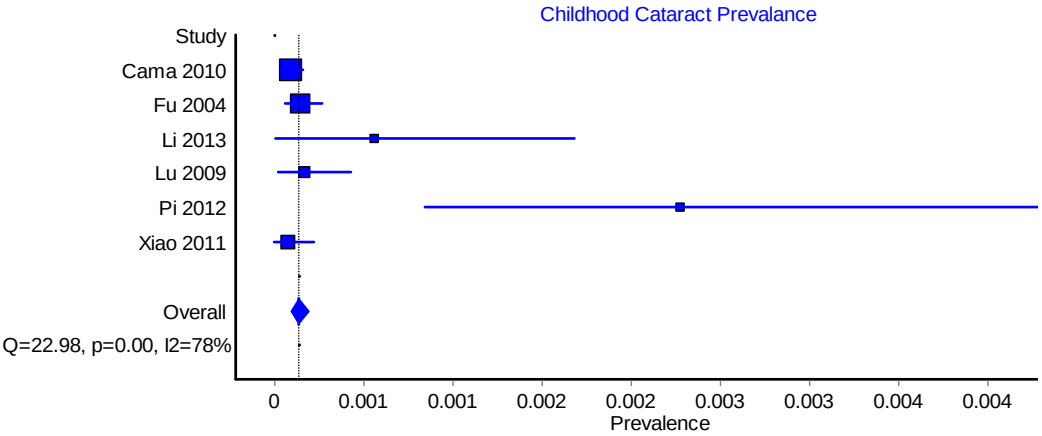


Figure 3.5 Forest plot of Childhood prevalence by country's economic status

Low income & Lower middle income economies



Upper Middle income economies



High income economies

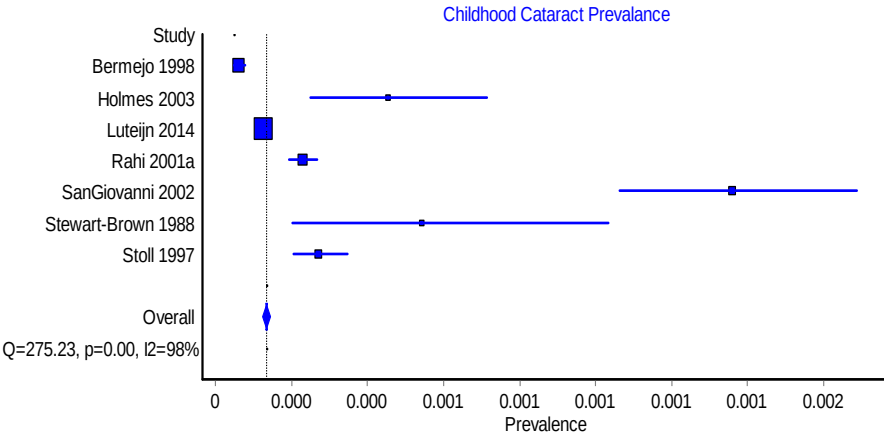


Table 3.5 Prevalence of childhood cataract per 10000 children of all included studies

Study	Prevalence	LCI 95%	Weight (%)
Bermejo 1998	0.63	(0.49 – 0.79)	15.92
Cama 2010	0.91	(0.40 – 1.62)	1.40
Dandona 1995	0.79	(0.35 – 1.41)	1.61
Demissie 2011	2.05	(1.03 – 3.40)	0.83
Dorairaj 2008	6.91	(2.28 – 13.76)	0.12
Duke 2013	0.33	(0.23 – 0.44)	16.42
Fu 2004	1.50	(0.65 – 2.66)	0.85
Holmes 2003	4.54	(2.50 – 7.17)	0.47
Li 2013	5.60	(0.08 – 16.86)	0.05
Limburg 2012	1.04	(0.13 – 2.64)	0.41
Lu 2009	1.70	(0.21 – 4.30)	0.25
Luteijn 2014	1.27	(1.15 – 1.39)	46.64
Nirmalan 2003	8.49	(3.71 – 15.08)	0.15
Pi 2012	22.73	(8.48 – 43.23)	0.04
Rahi 2001a	2.30	(1.94 – 2.68)	9.17
SanGiovanni 2002	13.59	(10.64 – 16.89)	0.76
Stewart-Brown 1988	5.45	(2.03 – 10.36)	0.18
Stoll 1997	2.73	(2.07 – 3.48)	3.01
Shirima 2009	0.42	(0.09 – 0.96)	1.35
Xiao 2011	0.74	(0.01 – 2.23)	0.38
Pooled	1.13	1.05	100
Statistics			
I-squared	95.9	94.7	
Cochran's Q	465.8		
Chi2, p	<0.0001		

3.4.3 Prevalence of childhood cataract regional wise

The heterogeneity of the included studies was high at over I^2 = 90% even when the studies are grouped according to their geographic regions. In the East Asia and Pacific region the heterogeneity was lower (Cochran's Q test, p<0.01; I^2 =75%), but this is also considered high

(Melsen et al., 2014). The overall prevalence of childhood cataract in East Asia and Pacific region was 1.29/10000 (95% CI: 0.87 – 1.8); North America 13.1/10000 (95% CI: 10.8 – 15.7), Europe & Central Asia 1.27/10000 (95% CI: 1.2 – 1.3), South Asia 1.4/10000 (95% CI: 0.83 – 2.12) and Sub Saharan Africa it was 0.38/10000 (95% CI: 0.28 – 0.5). The estimated prevalence in the North American region was ten times higher than in other regions. There are no previous reports of similarly high prevalence in this region, and as a high income economy there is no economic reason to suspect that the prevalence would be so much higher. The prevalence reported in sub Saharan Africa was much lower compared to all other regions, which may be related to the high under five children mortality rate in that region (http://www.who.int/blindness/causes/priority/en/index3.html) , as the child survival rate is very low in Sub Saharan African region.

3.4.4 Prevalence of childhood cataract in India

Three studies reporting prevalence data from India were included in this review and meta-analysis was performed for India alone. The estimated burden of childhood cataract in the country would set the context of this research. Heterogeneity of these studies were assessed and it was very high (I^2 – 92%) (Figure 3.7). The overall prevalence of childhood cataract in India was 1.4/10000 (95% CI: 0.83 – 2.12) (Table 3.6). The total population of India at the time of writing in (January 2017) is 1.34 billion (http://www.indiaonlinepages.com/population/india-current-population.html) and 29% (Approximately 389 million) are children aged less than 15 years. (National Health Profile 2015, published by Government of India). The extrapolation of this estimate to the population of children in India translates into 54,388 childhood cataracts (CI: 32481 to 82956) in the country. This estimate is very conservative as all the three studies included in this sub group analysis were conducted with the aim of estimating the childhood blindness and visual impairment and its causes. The criterion for blindness in these studies was better eye visual acuity. Due to this, the unilateral cases would be unlikely to be included in this estimate. Additionally, there are no data on incidence of childhood cataract from the country. This leaves a large gap in estimating the total burden of childhood cataract in India. However, even with the conservative estimate found in this review the problem of childhood cataract and the associated problem encountered both family and the communities are substantial.

Figure 3.6 Forest Plot showing the prevalence of childhood cataract in India

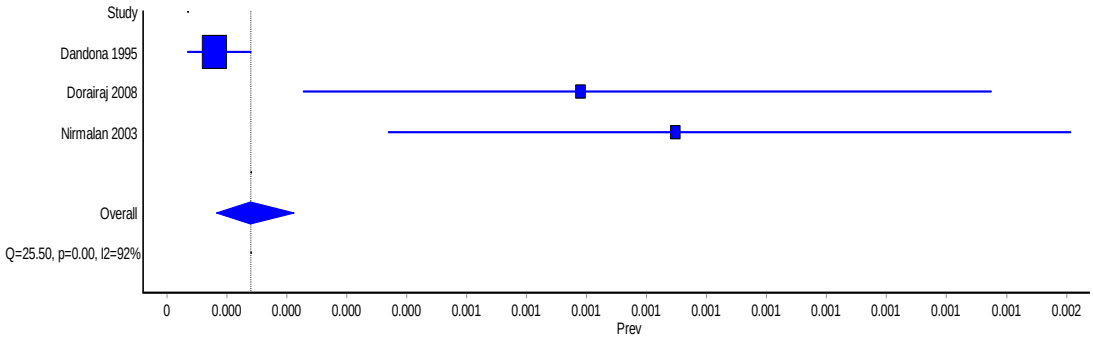


Table 3.6 Prevalence of childhood cataract per 10000 children in India

Study	Prevalence	CI 95%	Weight (%)
Dandona 1995	0.79	0.0035 - 1.41	85.47
Nirmalan 2003	8.49	3.71 – 15.08	7.99
Dorairaj 2008	6.91	2.28 – 13.76	6.54
Pooled	1.4	0.83 – 2.12	100
Statistics			
I-squared	92.16	80.28 – 96.88	
Cochran's Q	25.50		
Chi2, p	<0.0001		

Prevalence by Laterality

Prevalence by laterality was reported in four studies (Holmes et al., 2003, SanGiovanni et al., 2002, Stewart-Brown and Haslum, 1988, Xiao et al., 2011) and three studies reported data on traumatic cataract (Lu et al., 2009, Pi et al., 2012, SanGiovanni et al., 2002) (Table 3.7). Overall, the reported prevalence was similar in both unilateral and bilateral cataract (P = 0.21)

Table 3.7 Prevalence of childhood cataract by laterality in the included studies

Studies	Unilateral	Bilateral	Sample
Stewart-Brown 1988	3	4	14907
SanGiovanni 2002	38	35	53724
Holmes 2003	8	7	33021
Xiao 2011	0	2	27000
Total	49	48	128652
Overall Prevalence	0.000381	0.000373	
Prevalence per 10,000	3.808724	3.730995	

Prevalence by Gender

Prevalence was reported according to gender in four studies (Holmes et al., 2003, Limburg et al., 2012, SanGiovanni et al., 2002, Xiao et al., 2011) (Table 3.8). No significant difference in prevalence of childhood cataract was found between males and females (p = 0.48).

Table 3.8 Prevalence of childhood cataract by Gender in the included studies

Studies	Boys	Girls	Sample
Holmes 2003	4	11	33021
Limburg 2012	2	1	28800
Xiao 2011	2	0	27000
SanGiovanni 2002	37	36	53724
Total	45	48	142545
Prevalence	0.000316	0.000337	
Prevalence per 10,000	3.156898	3.367358	

3.4.5 Incidence of childhood cataract

Incidence was reported in four studies (Abrahamsson et al., 1999, Haargaard et al., 2004, Rahi et al., 2001b, Wirth et al., 2002) ranging from 2.2 to 10.8 per 10000; the laterality was reported in two studies (Abrahamsson et al., 1999, Rahi et al., 2001b) and gender breakdown was reported in three studies (Abrahamsson et al., 1999, Haargaard et al., 2004, Rahi et al., 2001b). The incidence of bilateral cataract was higher than the unilateral cataract, but not significantly (p= 0.35). The reported incidence was higher in boys compared to girls but again not significantly (p = 0.76).

Table 3.9 Summary of global prevalence of childhood cataract

Location	Prevalence	Range per 10 000
Global	Childhood cataract*	0.32 to 22.9 (median 1.03)
	Congenital cataract	0.63 to 9.74 (median 1.71)
Low income economies	Childhood cataract	0.42 to 2.05 (median 1.2)
Lower middle income economies		0.32 to 8.49 (median 1.0)
Upper middle income economies		0.74 to 22.7 (median 1.5)
High income economies		0.63 to 13.6 (median 2.7)

(* includes both congenital and developmental cataract)

3.5 Discussion

This is the first systematic review of all population prevalence and incidence studies of childhood cataract. The review found eighteen prevalence studies and four incidence studies of childhood cataract from five different geographical regions. The overall prevalence of childhood cataract was 1.14 /10000 and the incidence ranged from 2.2 to 10.8 /10000. The prevalence of childhood cataract in low and lower middle income economies was found to be 0.46 /10000 compared to 1.35/ 10000 in high income economies (see Table 3.9).

In contrast with our findings, previous published reports suggest that the prevalence of blindness due to childhood cataract is 10 times higher in low income economies compared to high income economies(Foster et al., 1997). One possible explanation for our finding of relatively low prevalence in low and lower middle-income economies is that the studies based from these economies included relatively small samples. The mean sample size of studies in low and lower middle income economies was 230,803 (including two key informant studies, with large samples) compared with 768,846 in high income economies. Our findings suggest that more studies with larger samples are needed to more closely estimate the prevalence of childhood cataract in low and lower middle income economies. As outlined earlier, this is challenging due to costs and the logistics involved, whereas in high income economies surveillance systems facilitate epidemiological data collection (Haargaard et al., 2004, Luteijn et al., 2014, Rahi et al., 2001a).

With respect to low and lower middle income economies, the estimate arrived based on this review is likely to be underestimated. This is due to a low number of studies with relatively small samples included in this review. Also the high prevalence of infant mortality rates in these countries and the strong association between infant mortality rate and the blindness in children has to be considered while interpreting the estimates from these regions (http://www.who.int/gho/child_health/mortality/mortality_under_five_text/en/).

The implications are, prevalence studies are used to inform researchers and policy-makers about burden of disease, thereby supporting the process of identification of priorities in healthcare prevention and policy. They are also needed for the development of health economics models to assess the impact of an intervention before any program implementation. The lack of prevalence data from lower and low middle-income countries found in this review indicates insufficient data on which to base policy prioritization for blindness prevention activities related to childhood cataract in these regions. In contrast, the established surveillance system in high income economies facilitates policies and programs such as new born screening programs to detect cataract in children for an early intervention. These findings suggest a need for further data on the prevalence of childhood cataract in lower and low middle-income countries.

Similarly, to take China (an upper middle income economy) as one example, prevalence studies included in this review were carried out in Beijing (1.7/10000) (Lu et al., 2009), South-Eastern China (0.7/10000) (Xiao et al., 2011), across all states (1.5/10000) (Fu et al., 2004)

and in Western China (22.7/10000) (Pi et al., 2012). The authors of the latter study commented that Western China is relatively undeveloped compared with other regions in the country, and this may illustrate the existence of a range of health care provision and prevalence within one country (Pi et al., 2012). Overall, however, the prevalence in upper-middle- and high-income economies was similar.

Incidence studies included in this review were conducted in Sweden (Abrahamsson et al., 1999), Denmark (Haargaard et al., 2004), UK (Rahi et al., 2001a) and Australia (Wirth et al., 2002). These are all high income economies; we found no incidence studies based in low to middle income economies. As outlined above, these prevalence estimates do not show particularly high prevalence in low income economies, but these findings are limited by a paucity of data in those regions, and the WHO estimates that prevalence is high in low to middle income economies (Reddy and Tan, 2001). This together with a complete lack of information on incidence in those economies suggests a strong need for epidemiological research to estimate the burden of childhood cataract.

Another important finding from this review is that both bilateral and unilateral cataract have similar prevalence, so about half of the cases are bilateral and about half are unilateral. Both have significant impact on vision in different ways. Unoperated bilateral cataract has the obvious impact of reducing vision in both eyes, thus causing severe visual impairment and blindness (Wilson ME, 2009) .

Unilateral cataract, on the other hand, has seemingly less impact, since it affects vision in only one eye, leaving the fellow eye able to provide unimpeded vision. However, it is important to note that bilateral visual deprivation during early childhood has a less severe impact on visual system development than unilateral deprivation (Birch et al., 1998). In particular, amblyopia is a condition in which vision is abnormal (reduced acuity and other aspects of visual function) as a result of abnormal visual stimulation during early life. As discussed in the chapter 1, treatment to correct visual abnormality is more successful in early childhood, during a period of visual system plasticity, than later, so early diagnosis and management is important for any childhood condition in which vision is impeded (Sengpiel, 2014, Medsinge and Nischal, 2015).

Unequal stimulation of the right and left eye in unilateral childhood cataract results in poor vision through the affected eye and normal vision through the fellow eye. On the other hand, equal stimulation of the right and left eye (equally impeded for both eyes) in bilateral childhood cataract results in less severe visual abnormality of each eye (Birch, 2013). As mentioned above, in either situation, treatment is largely unsuccessful beyond early childhood, so cataract surgery and vision correction must be carried out at an early age to avoid amblyopia. In unilateral cataract which is untreated in childhood, reduced vision in one eye persists through adulthood, binocular depth perception is poor, and the individual is susceptible to visual loss (Birch et al., 1998). Thus early treatment in both cases is important; to remove the cataract as in impediment to vision, in bilateral cases to remove the impediments and to prevent and treat mild bilateral amblyopia, and in unilateral cases to prevent and treat moderate to severe unilateral amblyopia. Consistent with this, the appropriate provision of surgery for congenital cataracts is one of the specific disease control objectives in the Vision 2020 program to control blindness in children (Gilbert and Foster, 2001b, Pizzarello et al., 2004).

Various methods have been developed and validated for the assessment of vision in infants and young children. The preferential looking method, for example, provides a simple, portable means of assessing visual acuity in infants and children, but relies to some extent on the child's motivation and on the observer's assessment of the child's response. In this method a remote eye tracker used to measure eye movement responses to different visual stimuli. From the reflexive eye movement responses, output parameters such as reaction times, fixation accuracy and fixation duration are calculated to quantify a child's viewing behaviour. Through this approach, the quality of visual information processing can be assessed without the use of communication in young children (Kooiker et al., 2016).

Objective methods such as the visual evoked potential and optokinetic nystagmus may be expensive in some cases and/or require specific knowledge and skills (Anstice and Thompson, 2014). The studies included in this review have generally used more basic methods to estimate vision in children, such as infants' detection of small objects, or observation of a light (refer Table: 3.4). These methods cannot provide an accurate indication of acuity, and simple, affordable methods such as preferential looking cards would provide a better means of gauging the severity of vision loss in prevalence studies on childhood cataract.

Reliability of diagnosis is of fundamental importance in a prevalence study. In the studies we have reviewed, no explanation was given of the diagnostic method used. Some studies indicated that a slit lamp was used, for example, but did not explain on what basis (e.g. grading scheme) cataract was diagnosed using the slit lamp. It has been suggested that both subjective and objective evaluations of the infantile cataracts are important to predict its effects on visual performance (Forster et al., 2006).

The global prevalence of childhood cataract in this review was 1.14 /10000 children. With an estimated 26% of the global population aged <15 years (Randrianaivo et al., 2014) (1.86 billion children in this age group), this would translate to a global prevalence of 212,285 childhood cataract. In addition, there will be around 400,000 to 2 million new childhood cataract cases every year.

Limitations

The use of a quality assessment tool is key in any systematic review as it allows original research to be objectively appraised. While several high quality appraisal tools are available for appraisal of randomised trials (e.g. the Cochrane Risk of Bias tool; http://methods.cochrane.org/bias/assessing-risk-bias-included-studies) relatively few are designed for appraisal of observational epidemiological studies. In the present review the quality assessment tool includes 10 questions focussed on key indicators of research quality such as possible bias in sampling and in identification or measurement of the condition. It does not address, however, authors' conflict of interest, a factor which may potentially introduce bias, so not all sources of bias were considered in the present review.

A lack of epidemiological data from lower and low middle income economies might have affected the overall estimate reported in this review. It is possible that the reported prevalence in these regions has been underestimated by the existing studies and hence the findings should be interpreted with caution until more data are available. Though this review has called for more epidemiological data from these regions, it needs to be considered that epidemiological studies are very expensive, more so when the prevalence is very low in the population.

Though there are limitations in this review, these conservative estimates should inform the policy makers to prioritise funding, programs to reduce blindness due to childhood cataract at

regional and global levels. Furthermore, timely surgical intervention (Gilbert CE, 2003) and appropriate follow-up after surgery would avoid blindness in children due to cataract, as emphasised and advocated by the Vision 2020 initiative: The Right to Sight Initiative (Thylefors, 1998a).

3.6 Conclusion

This review highlights substantial gaps in the epidemiological knowledge of childhood cataract worldwide. Although findings from high income and upper middle income economies are consistent, very little is known on prevalence, and nothing on incidence, from low and lower middle income economies, where the burden of childhood cataract is presumed to be high. This lack of epidemiological data has many implications on the policy decisions, particularly in resource allocation. The estimated prevalence and incidence reported in this review to be considered with caution considering the lack of representative data from low and lower middle income economies. Future studies should report age, sex and ethnicity-specific estimates of incidence and prevalence, and standardize findings to a common population.

Chapter – 4

4 Age at presentation for childhood cataract surgery across India

Summary

This chapter starts with a description of the significance of assessing the age at surgery for childhood cataract in India. It further explains the methodology adopted in this assessment and the results and interpretation of the findings. The results were reported for the entire study participants and by region wise. Data on traumatic cataract was analysed and presented separately as a separate section in this chapter. The results from this section highlight the significance of this problem in India and justify the need to explore and understand the barriers for accessing childhood cataract services in the country.

4.1 Introduction

Cataract is an avoidable cause of childhood vision impairment and blindness and is responsible for 5% to 20% of blindness in children (Foster et al., 1997) and is a priority for the VISION 2020: Right to Sight Initiative (Thylefors, 1998b). A recent systematic review on the global burden of childhood cataract reported prevalence estimates ranging from 0.32 to 22.9 per 10000 children (Sheeladevi et al., 2016). Although a treatable condition, previous research from India indicates that about half of the children in schools for the blind suffer from potentially preventable and or treatable conditions with cataract being one of the leading causes (Titiyal et al., 2003).

Cataract in early childhood can be clinically classified as either ‘congenital’ or ‘developmental’ the former deemed to have greater impact on vision. This categorization [congenital and developmental] is imprecise and unsatisfactory since it is almost impossible to know the age of onset with most commence during fatal life. (Taylor, 1998) However, these terms are used in many countries and provide a clinical dichotomous indication of impact on vision, and are used as such here.

Cataract in children may be unilateral or bilateral (Gralek et al., 2007) and other than cataracts caused by trauma and infections, most childhood cataract is formed in utero.

The developing visual system requires appropriate visual experience during infancy and early childhood. If compromised, bilateral or unilateral (Birch, 2013) form deprivation amblyopia results which affects the child's educational (Pratt and Bryant, 1990) and psycho social development. Thus, while treatment of adult cataract is effective for visual rehabilitation at any age, a cataract that occurs in infancy and early childhood must be treated early on, and requires long-term follow-up.

The time at which treatment of congenital cataract is most effective is within the first six to eight weeks after birth for unilateral disease (Birch et al., 1998, Birch and Stager, 1996), and within the first 14 weeks, for bilateral cases (Birch et al., 2009). Previous reports suggest that late diagnosis limits the scope for successful surgical treatment (Chak et al., 2006, Taylor et al., 2001).

In developed countries, routine screening of all babies in the neonatal period facilitates early recognition of any lens opacity and timely surgical intervention (Fallaha and Lambert, 2001, Magnusson et al., 2003, Rahi and Dezateux, 1999). Despite this in the UK even with routine examination only half of all cataracts in children were diagnosed by the first year of age (Chak et al., 2006, Fallaha and Lambert, 2001). However, in developing countries, where neonatal eye screening is not routine as part of the health system cataract surgery in children is delayed due to late recognition (usually at least a few months after birth) with correspondingly later presentation at hospital for treatment (You et al., 2011). The possible reasons for delayed recognition and treatment vary geographically and include lack of new born screening programs, lack of knowledge among the parents /carers and limited accessibility to specialist centres (You et al., 2011).

Most of the unilateral cataract in children were due to eye injuries and Paediatric traumatic cataract is one of the leading causes of monocular blindness in children, accounting for 29%-57% of all paediatric cataract cases (Tomkins et al., 2011). As described earlier the children eye is in development, any eye trauma in early years will lead to more severe complications. Without effective and prompt treatments, paediatric cataract will deteriorate vision, including loss of binocular vision, amblyopia, strabismus, low vision or blindness (Acuna and Yen, 2009). Traumatic cataract in children can present many medical and surgical challenges to the ophthalmologist. Careful examination and a management plan can simplify these difficult cases and provide the best possible outcome (Sarikkola et al., 2005). Eye injuries occur mostly in children when they are playing without any supervision (Karim-Zade et al., 2016)

and playing with tools that are unsafe and unprotected. For example, a study from rural India reported that most of the ocular injuries in children were caused while handling house hold items like pins, scissors, knives, pens and pencils (Gogate et al., 2012). These objects can cause penetrating injury in the eyes damaging the lens. The lens damage can vary and can cause either a small localized cataract to a total cataract disruption. Eyes with traumatic cataract were more likely to develop posterior capsular opacification (PCO) after surgery than eyes without traumatic cataract (Trivedi and Wilson, 2015). The results also suggest that PCO develops faster in eyes with traumatic cataract, hence it was recommended to consider Primary posterior capsulotomy and vitrectomy for children having traumatic cataract surgery, irrespective of age at the time of surgery.

In general, the eye injuries are classified as blunt and penetrating and require a multi-disciplinary team of professionals including a paediatric ophthalmologists, cornea and anterior segment experts and anaesthetist for surgical management and specialist optometrist for providing post-operative correction and amblyopia therapy and treatment (Adlina et al., 2014).

Early presentation for surgery, inadequate follow up and poor post-operative visual outcome in paediatric patients remain challenging in low and lower middle income countries (Gogate et al., 2010, Yorston et al., 2001). There have been a few large-scale population-based studies investigating delay in paediatric cataract surgery (Bronsard et al., 2008, Mwende et al., 2005, Yorston et al., 2001). Retrospective data from India indicate that only 50% of children with cataract presented at the hospital for surgery without delay (Gogate et al., 2010).

As discussed in the introduction and methodology chapter, with the given diversity in India, wider geographical coverage was considered logical for meaningful comparison. Currently, no prospective data are available on the age at presentation for cataract surgery across India.

The main aim of this study was to investigate the following:

- The age at recognition and presentation for cataract surgery among children at hospitals located across India. (Age at recognition was calculated based on when the parents' / carers' or others recognized something abnormal with the child's eye that lead to the process of accessing the cataract services and age at presentation for

cataract surgery was calculated based on the date the child was admitted for cataract surgery) and the secondary aims were:

- To identify all socio demographic factors associated with any delay in undergoing surgery.
- To calculate age variations across different geographical regions separately for congenital and developmental cataract
- To identify any gender differences in age at presentation for childhood cataract surgery.
- To calculate the age at cataract surgery in children after eye injuries and to report the type of injuries.

4.2 Methods

This multicentre prospective observational study was conducted in India between Nov 2015 and March 2016. A detailed description of the rationale for using this methodology is explained earlier in Chapter 2. This study was approved by the School of Health Sciences Research Ethics Committee at City, University of London and by the Institutional Review Boards of all nine participating hospitals in India and the principles of the Declaration of Helsinki were followed throughout. The study sites were three hospitals within the owned by L V Prasad Eye Institute (LVPEI) network and six partner hospitals of Orbis international. The list of nine participating hospitals were listed earlier in Chapter 2.

The interviewers prospectively approached the parents or carers of all children (aged < 18 years) admitted for cataract surgery between 16th Nov 2015 to 5th March 2016, and those who gave consent were enrolled. At each centre, a member of staff was trained for this project by the principal investigator (SS) so that a consistent approach was used within and across all centres. In addition, one paediatric ophthalmologist was the clinical lead at each centre fully appraised about the study aims and methodology. This person's role was to address any questions arising locally during the study.

Parents were interviewed using a questionnaire which was developed initially in English and piloted before the main study. During pilot testing the principal investigator administered the questionnaire at one study centre and checked the sequence and comprehension of the questions. Based on this process, minor modifications were made and the finalized questionnaire was translated to Telugu, Hindi, Malayalam, Marathi, Bengali and Assamese

languages and back-translated to ensure accuracy and consistency of content. More details on the questionnaire finalization was discussed in Chapter 2.

The questionnaire was based on a literature review with the aim of estimating the age of recognition and presentation for childhood cataract surgery, and the barriers associated with accessing surgery on time. It consists of four major sections and the complete questionnaire is included as Appendix 3.

1. Socio-demographic details of the child and the family
2. Age at identification and the process involved in accessing surgical treatment
3. Barriers to accessing cataract services
4. Clinical details (gathered from the patient's record on the same day as the questionnaire was administered).

The study team at each hospital identified children admitted for surgery and approached the parents or care providers individually to explain the purpose of the study. All participants were provided with written information. The questionnaire was administered verbally in the participant's native language.

As a quality check, all of the enrolments were cross-checked with the medical records by the principal researcher and 10% of the interviews were observed in person by the principal researcher in each of the nine hospitals.

4.2.1 Case Definitions

In the literature there is considerable ambiguity on the classification of developmental cataract and this has been discussed in detail later in the discussion. For this study the Paediatric ophthalmologists at the study sites followed uniform criteria to diagnose and to classify it as either congenital or developmental cataract in children (see Table 4.1).

Table 4.1 Criteria followed for classification of childhood cataract

Type of cataract	Criteria for classification
Congenital	• Recognised at or within two months of birth or • accompanied by nystagmus and • with no other pathology
Developmental	• Recognised after two months from birth and • zonular in nature and • without nuclear involvement
Traumatic	• Associated with any eye injuries in the past

In case of total cataract, where the lens is completely covered and dense, the decision was primarily based on the history of the onset of the cataract and was classified accordingly.

4.2.2 Late presentation

For all congenital cataracts, surgery completed more than 12 months from birth was defined as late surgery. Although it is recommended to operate earlier than this for better visual outcomes (Birch et al., 2009), this definition was considered for pragmatic reasons. Time to surgery (time period between recognition and surgery) was more complex in developmental cases, in which either the cataract was not deemed to be causing significant visual loss or the progression was slow. Developmental cataract is typically recognised when it becomes visually significant at which point it may have been under observation by an ophthalmologist for some time until it was considered appropriate to operate. Considering these factors, a separate analysis was attempted to identify the factors associated with early presentation only in congenital cataract cases and also combining both congenital and developmental cases and the factors associated with the presentation of surgery for childhood cataract in different age intervals.

4.2.3 Statistical analysis

Data were entered into an Excel database and analyses were performed using SPSS version 22. Descriptive statistics, including mean, standard deviation and standard error were calculated. The standard deviation is most often used to refer to the individual observations and describes the variability of the individual observations while standard error shows the variability of the estimator. A Chi square test was used to determine any differences in various socio demographic variables between the genders at the time of presentation for cataract surgery.

An independent samples t test was used to determine if the mean age at surgical presentation were different across a number of socio demographic variables. All the independent variables were grouped into two categories for this analysis. We considered mean age as the independent variable and compared the dependent variables such as gender (boys and girls), treatment category (paying and non-paying), place of birth (Hospital and Home) , family history of childhood cataract (Yes and No), laterality (Bilateral and Unilateral), residential location (Rural and Urban), parental consanguinity (yes and No), region (South West region and North Eastern region), parents education (no education and any education), parents occupation (fathers – labourers and all others; mothers – not working and working), family's monthly reported income (less than INR 5000 and more than INR5000; (£1 equals approximately INR85)) and the cataract type (congenital and developmental).

All those variables found to be independently significant with the age at presentation for childhood cataract surgery were considered for multivariate analysis. A linear regression analysis was performed to predict factors associated with the age at childhood cataract.

One way ANOVA test was used to calculate the variance within and across the regions for age at presentation for childhood cataract.

Regression analysis

Univariate and multiple logistic regression analyses were used to look for associations between time to surgery for congenital cataract and a number of predictor variables e.g. gender, laterality, parental age and education, family history of cataract and number of siblings. All the socio demographics factors for the child and the family were considered independently and as a group. Results were presented as odds ratios (OR) with 95%

confidence intervals (CIs), and a p-value of <0.05 was considered statistically significant. Regression analysis was performed separately for congenital cataract and for other non-traumatic cataract such as congenital and developmental cataract together.

The results were analysed for congenital and development cataract as one subset and in this study a total of 179 traumatic cataract cases were enrolled and the findings are presented as second subset in the results.

4.3 Results

A total of 780 children were admitted for cataract surgery during the study period, of which 751 (96%) participated in the study. The remaining 4% declined to participate. No participants were excluded by the study team. The details of the 751 childhood cataract cases by hospital and cataract type are presented in Table 4.2.

Table 4.2 Details of the participant's recruitment by study centre

S. No	Study centre	Region	Total no of subjects n (%)	Cataract Type		
				Congenital n (%)	Developmental n (%)	Traumatic n (%)
1	L V Prasad Eye Institute (LVPEI), Hyderabad, Telangana	South	185 (24.6)	95 (32.9)	66 (23.3)	24 (13.4)
2	L V Prasad Eye Institute (LVPEI), Visakhapatnam, Andhra Pradesh		33 (4.4)	19 (6.6)	8 (2.8)	6 (3.4)
3	L V Prasad Eye Institute (LVPEI), Vijayawada, Andhra Pradesh		41 (5.5)	29 (10.0)	6 (2.1)	6 (3.4)
4	Little Flower Hospital & Research Centre, Angamaly, Kerala		34 (4.5)	15 (5.2)	12 (4.2)	7 (3.9)
5	PBMA's H V Desai Eye Hospital, Pune, Maharashtra	West	38 (5.1)	16 (5.5)	14 (4.9)	8 (4.5)

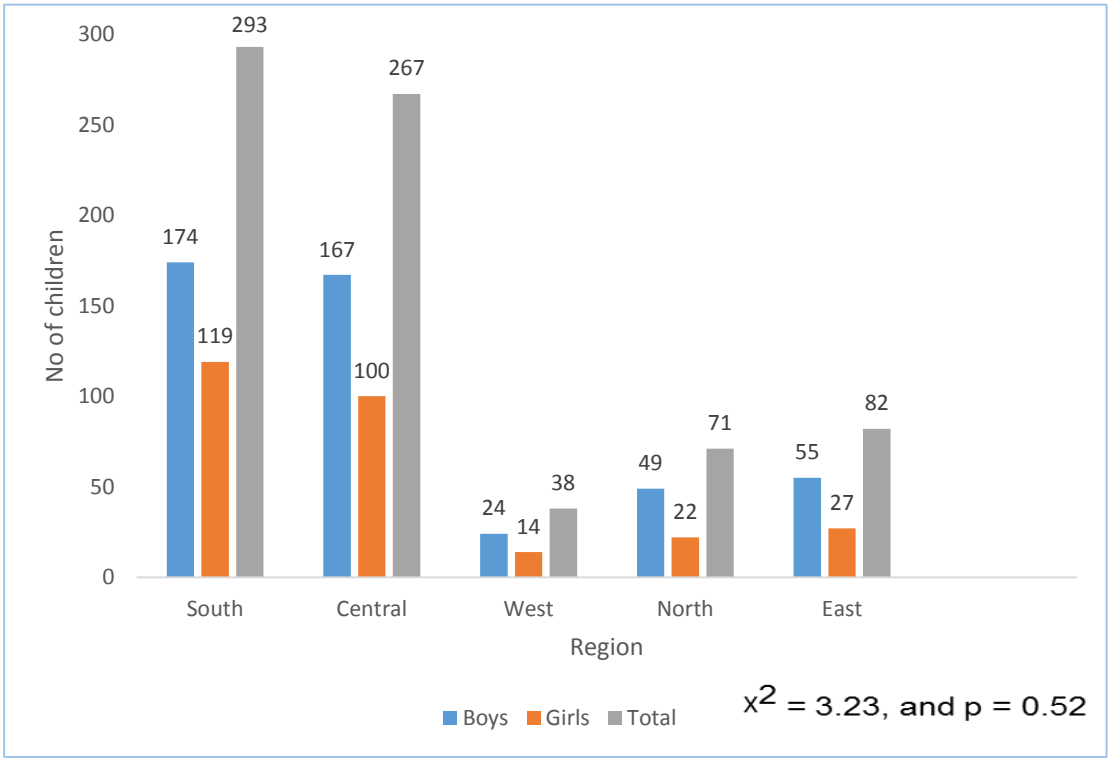
Table 4.2 Details of the participant's recruitment by study centre

S. No	Study centre	Region	Total no of subjects n (%)	Cataract Type		
				Congenital n (%)	Developmental n (%)	Traumatic n (%)
6	Dr. Shroff's Charity Eye Hospital, Delhi	North	71 (9.5)	30 (10.4)	25 (8.8)	16 (8.9)
7	Sadguru Netra Chikitsalaya, Shri Sadguru Seva Sangh Trust, Chitrakoot, Madhya Pradesh	Central	267 (35.6)	49 (17.0)	125 (44.2)	93 (52.0)
8	Vivekananda Mission Ashram, Netra Niramaya Niketan, Haldia, West Bengal	East	54 (7.2)	28 (9.7)	13 (4.6)	13 (7.3)
9	Sri Sankaradeva Nethralaya , Guwahati, Assam	North East*	28 (3.7)	8 (2.8)	14 (4.9)	6 (3.4)
Total			751 (100)	289 (100)	283 (100)	179 (100)
* North East region is grouped into Eastern region for further analysis.						

Nine hospitals representing 5 geographic regions: South (n= 4); West (n= 1); Central (n= 1); East (n=2) and North (n=1) in eight states across India participated in this study and the region wise subjects enrolled is presented in Table 4.4.

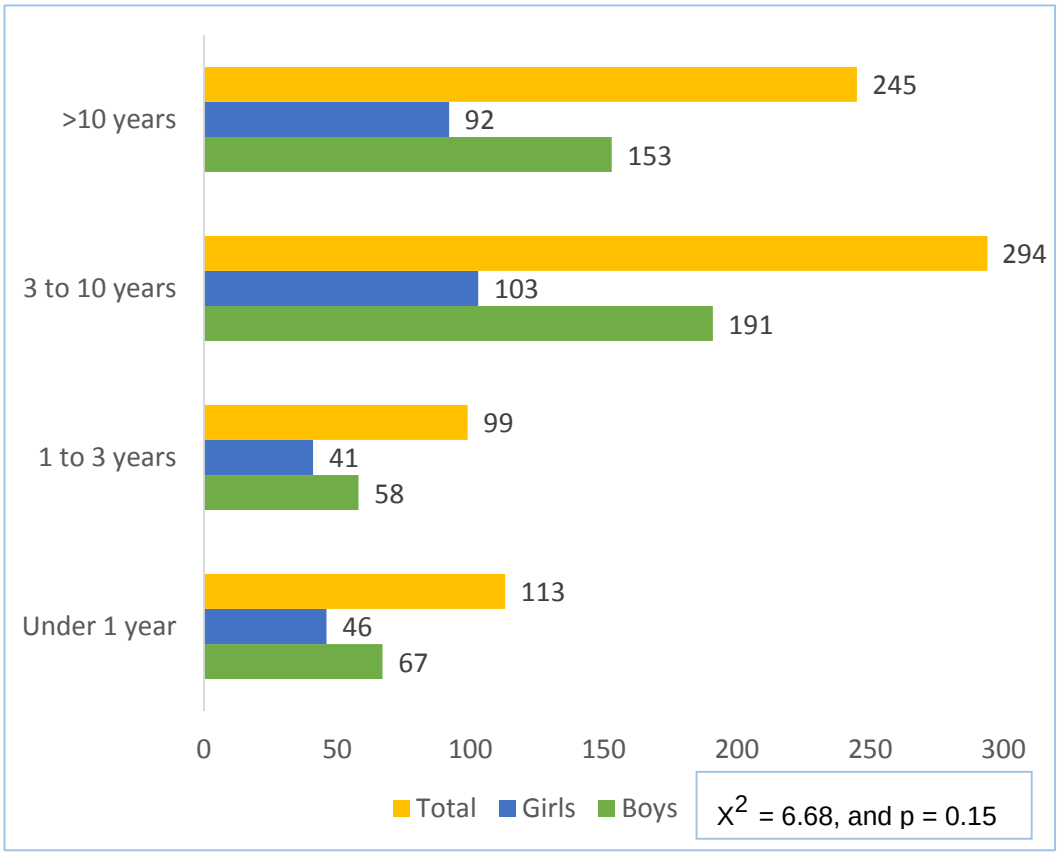
Of the 751 subjects, 469 (62.5%) were boys and 282 (37.5%) were girls and see Figure 4.1 for the number of boy and girl participants in each region.

Figure 4.1 Region wise enrolment of subjects by Gender



Fewer girls than boys enrolled in each region and this trend did not differ across all the regions (p = 0.52) (Figure 4.1). Consistent with this, fewer girls accessed cataract surgery across all age groups (p = 0.15) (Figure: 4.2)

Figure 4.2 Number of children enrolled by gender in different age categories

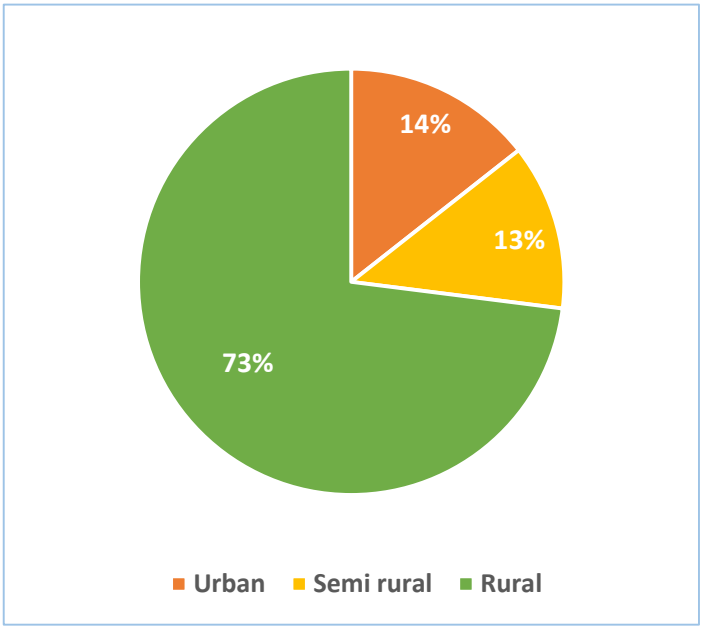


The location from which the children are accessing cataract services is an important demographic factor in this research. Paediatric eye care, especially the surgical facility is considered as a specialty service. It requires a team of eye health professionals to manage the cases, including paediatric ophthalmologist, anaesthetist, specially trained optometrists for managing the children's optical correction, orthoptist for managing amblyopia and other specialists who can contribute to the welfare of the children. Considering the number of specialists required and given the low prevalence of surgical care in children, the majority of paediatric eye care services are available only in major cities for achieving operational efficiency. Hence, the children from rural and semi-rural areas have to travel long distance to receive the care. However, in this research, a majority of the participants were from rural[8]

[8] Villages under the panchayat administrative system, which is an elected village council in India

areas and almost equal percentages of participants from semi-rural[9] and urban regions accessed the services and the details are shown as Figure 4.3.

Figure 4.3 Residential location of the study participants enrolled in this study



4.3.1 Congenital and Developmental Cataract

As defined earlier in the methods section, congenital cataract and developmental cataract in children are formed in utero and are classified into two of these categories based on standard criteria. Also, these types of cataract are non-traumatic in nature. In this research, a total of 572 cases had non-traumatic cataract and this results section presents data relating to congenital and developmental cataract cases only. About half (51%) of the 227 underwent surgery within 1 year of birth, 19.4% between 1 and 3 years, 20.3% between 3 and 10 years and around 9% after 10 years of age.

Overall the mean age of both congenital and developmental cataract cases at the time of hospital admission for surgery was 74.6 months (SD 55.8). The mean age at surgery of

[9] A small town with under 20,000 or 25,000 inhabitants, which is formed under the panchayat administrative system

congenital and developmental cataract was 48.2 (SD: 50.9) and 101.6 months (SD: 46.9) respectively. The mean age at surgery by cataract type and gender is presented in Table 4.3.

Table 4.3 Mean age (in months) for childhood cataract surgery by type and gender

Type of cataract	Boys				Girls				Total			
	n	mean	SD	SE	n	mean	SD	SE	N	mean	SD	SE
Congenital	167	48.9	50.9	3.9	122	47.1	51.1	4.63	289	48.2	50.9	2.9
Developmental	169	97.9	46.9	3.61	114	107.0	46.6	4.37	283	101.6	46.9	2.8
Total	336	73.6	54.7	2.9	236	76.1	57.4	3.7	572	74.6	55.8	2.3

SD – standard deviation; SE – Standard error of mean

Table 4.4 Region wise summary of subjects participated in this study

Region Name	Non traumatic cataract n (%)	Traumatic cataract n (%)
South	250 (43.7)	43 (24.0)
West	30 (5.2)	8 (4.5)
Central	174 (30.4)	93 (52.0)
North	55 (9.6)	16 (8.9)
East	63 (11.0)	19 (10.6)
Total	572 (100)	179 (100)

* Non traumatic cataract includes congenital and developmental cataract

According to the study definition, 289 (38%) of the children presented with congenital cataract, 269 (36%) children with developmental cataract. The latter included 14 (2%) children diagnosed with cataract caused by infections or diabetes and categorised as developmental cataract for the purpose of further analysis. Bilateral cataract was present in 493 (65.6%) children, and unilateral cataract was present in 258 (34.4%) children. Laterality by region is presented in Table 4.5. Of the 289 cases of congenital cataract, 257 (88.9%) were bilateral and 32 (11.1%) unilateral.

Table 4.3 Laterality of the participants by region

Region	Bilateral			Unilateral		
	Congenital n (%)	Developmental n (%)	Total n (%)	Congenital n (%)	Developmental n (%)	Total n (%)
South	139 (48.1)	78 (27.6)	217 (37.9)	19 (6.6)	14 (4.9)	33 (5.8)
West	15 (5.2)	12 (4.2)	27 (4.7)	1 (0.3)	2 (0.7)	3 (0.5)
Central	40 (13.8)	100 (35.3)	140 (24.5)	9 (3.1)	25 (8.8)	34 (5.9)
North	29 (10.0)	22 (7.8)	51 (8.9)	1 (0.3)	3 (1.1)	4 (0.7)
East	34 (11.8)	24 (8.5)	58 (10.1)	2 (0.7)	3 (1.1)	5 (0.9)
Total	257 (88.9)	236 (83.4)	493 (86.2)	32 (11.1)	47 (16.6)	79 (13.8)

Age of the child at the time of surgery is an important factor for achieving better visual outcomes after surgery. As described earlier, early surgery is recommended in children with cataract and Table 4.6 shows the proportion of children who completed surgery under different age categories in each region. Three quarters of all childhood cataracts operated before 1 year of age in this study were performed in the Southern region. This reflects the fact that childhood cataracts are identified and operated early in this region.

Table 4.4 Proportion of participants in different age groups by region

Region	Age group					
	< 6 months	≥ 6 months and ≤ 1 years	≥ 1 year to 3 years	≥ 3 years to 10 years	≥ 10 years	Total n (%)
South	60 (76.9)	25 (75.8)	53 (58.9)	75 (34.9)	37 (23.7)	250 (43.7)
West	3 (3.8)	0 (0.0)	8 (8.9)	15 (7.0)	4 (2.6)	30 (5.2)
Central	6 (7.7)	3 (9.1)	24 (26.7)	69 (32.1)	72 (46.2)	174 (30.4)
North	7 (9.0)	1 (3.0)	2 (2.2)	20 (9.3)	25 (16.0)	55 (9.6)
East	2 (2.6)	4 (12.1)	3 (3.3)	36 (16.7)	18 (11.5)	63 (11.0)
Total	78 (100)	33 (100)	90 (100)	215 (100)	156 (100)	572 (100)

The main subjects for this study are children with cataract and the decision to seek care for surgery depends on the parents' /carers' health seeking behaviour. Socio demographic factors including gender, age and education of the parents, location of residence and the parental income may determine this behaviour. Most of the socio demographic factors were found to be similar in both genders. Table 4.7 shows the various socio demographics of the child and their parents according to the gender of the child.

Table 4.5 Socio demographic details of the study participants by gender

Variables	Boys n (%)	Girls n (%)	Total n(%)	P value*
Cataract Type				
Congenital	167 (29.2)	122 (21.3)	336 (58.7)	0.67
Developmental	169 (29.5)	114 (19.9)	236 (41.3)	
Laterality				
Bilateral	291 (50.9)	202 (35.3)	493 (86.2)	0.81
Unilateral	45 (7.9)	34 (5.9)	79 (13.8)	
Family History of Childhood cataract	34 (48.6)	36 (51.4)	70 (12.2)	0.07
Treatment category				
Paying	175 (30.6)	118 (20.6)	293 (51.2)	0.67
Non paying	161 (28.1)	118 (20.6)	279 (48.8)	
Place of birth				
Hospital	234 (40.9)	154 (26.9)	388 (67.8)	0.28
Home	102 (17.8)	82 (14.3)	184 (32.2)	
Residential location				
Urban	54 (9.4)	34 (5.9)	88 (15.4)	
Semi-rural	47 (8.2)	29 (5.1)	76 (13.3)	0.68
Rural	235 (41.1)	173 (30.2)	408 (71.3)	
Region				
South India	139 (24.3)	111 (19.4)	250 (43.7)	
Central India	102 (17.8)	72 (12.6)	174 (30.4)	
West India	18 (3.1)	12 (2.1)	30 (5.2)	0.54
North India	36 (6.3)	19 (3.3)	55 (9.6)	
East India	41 (7.2)	22 (3.8)	63 (11.0)	

(*p value is reported based on chi squared test)

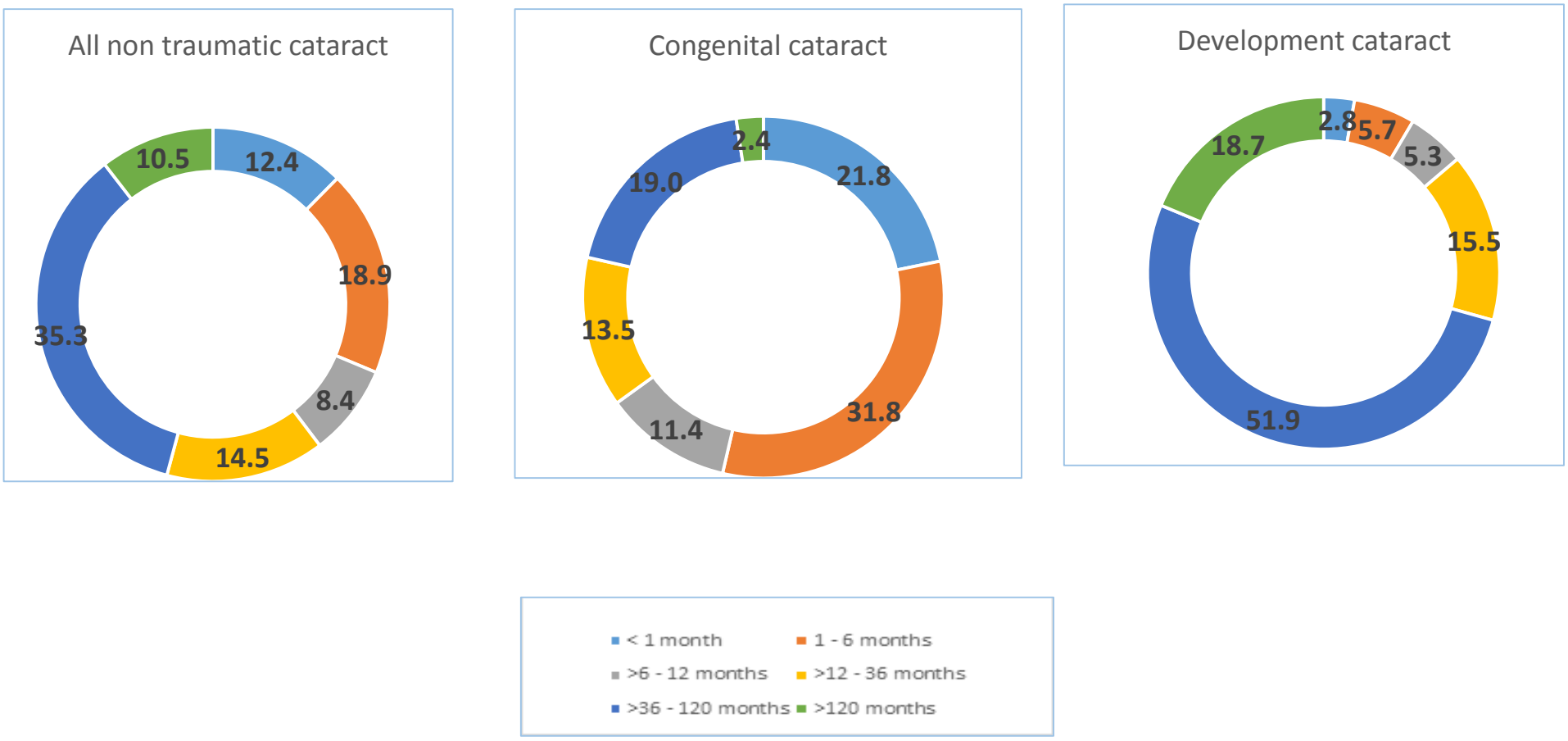
Table 4.7 Socio demographic details of the study participants by gender				
Variables	**Boys n (%)**	**Girls n (%)**	**Total n(%)**	**P value**
Parental consanguinity				
Yes	88 (57.1)	66 (42.9)	154 (26.9)	0.70
Father's education				
No education	87 (15.2)	83 (14.5)	170 (29.7)	
School education	202 (35.3)	118 (20.6)	320 (55.9)	0.04
University education	47 (8.2)	35 (6.1)	82 (14.3)	
Mother's education				
No education	113 (19.8)	91 (15.9)	204 (35.7)	
School education	188 (32.9)	110 (19.2)	298 (52.1)	0.06
University education	35 (6.1)	35 (6.1)	70 (12.2)	
Father's occupation				
Daily Labourer	235 (41.1)	170 (29.7)	405 (70.8)	
Formal employment (government / private sector)	67 (11.7)	36 (6.3)	103 (18.0)	0.27
Others	34 (5.9)	30 (5.2)	64 (11.2)	
Mother's occupation				
Not working	256 (44.8)	174 (30.4)	430 (75.2)	
Daily Labourer	69 (12.1)	48 (8.4)	117 (20.5)	0.31
Formal employment (government / private sector)	11 (1.9)	14 (2.4)	25 (4.4)	
Family's reported monthly income				
(£1 = INR 85 approximately)	146 (25.5)	110 (19.2)	256 (44.8)	
< INR 5000	171 (29.9)	104 (18.2)	275 (48.1)	0.12
INR 5001- INR 20,000	19 (3.3)	22 (3.8)	41 (7.2)	
>INR 20,001				

(*p value is reported based on chi squared test)

4.3.2 Cataract recognition

As discussed earlier (Chapter 1), red reflex screening for identifying children with cataract is not a routine practice in India. Hence, in young children, cataract or any eye problems need to be recognized by others such as parents / carers or health care providers, while some older children may be able to recognize their vision problems and report either to their parents or to school teachers. In cases of congenital cataract, responsibility for the recognition lies with parents, midwives, traditional birth attendants and paediatricians. However, the responsibility for seeking treatment solely lies with the parents. Parents' ability to recognize the problems in their child is determined by the knowledge and awareness of the condition (Senthilkumar et al., 2013b). In addition to knowledge and awareness there are many other factors associated with delay in seeking care, which will be discussed in later chapters on barriers to access cataract services in children. Figure 4.4 shows the age at recognition for congenital and developmental cataract.

Figure 4.4 Age categories of cataract recognition by cataract types



Around 43% of the congenital cataracts were recognized within 6 months and more than half of all developmental cataracts were recognized between the age of 3 and 10 years. This is likely due to slow progression of growth and its effects on the vision. Overall, in 227 (40%) of the children with either congenital or developmental cataract, the condition was recognized before 1 year of age and of these 71 (12.4%) were recognized during the neonatal period (0–28 days). While recognition of a problem is an important step it does not necessarily result in immediate access to the health care facilities for seeking care, as presented in Table 4.11.

In 286 (50%) of the subjects a parent recognized the eye problem, in 81 (14.5%) it was recognized by another relative including grandparents or older siblings. In 149 (26%) cases it was recognized by health workers and in 56 (10%) cases, the cataract was recognized by others, mainly school teachers. The relationship to child of person who recognised the problem by the cataract type is presented in Table 4.8.

Table 4.6 Relationship to child of person who first recognised the cataract in children and the cataract categorization

Cataract recognised by	Type of cataract		Total
	Congenital	Developmental	
Parents	155 (27.1)	131 (22.9)	286 (50.0)
Other family member	35 (6.1)	46 (8.0)	81 (14.2)
Health worker	80 (14.0)	69 (12.1)	149 (26.0)
Teacher	19 (3.3)	37 (6.5)	56 (9.8)
Total	289 (50.5)	283 (49.5)	572 (100)

Table 4.9 shows the various types of changes identified by the parents and carers. In congenital cataract, cloudiness or whiteness in the eye was identified in 29% of the children and similarly, in developmental cataract cases the most identified problem was poor vision in 23%. Overall, the type of changes identified in congenital and developmental cataract were significantly different ($p<0.001$).

Table 4.7 Type of changes identified at the time of recognizing eye problem

Type of changes	Cataract Type		Total n (%)
	Congenital	Developmental	
Cloudiness / Whiteness	163 (28.5)	78 (13.6)	241 (42.2)
Eye rubbing	4 (0.7)	4 (0.7)	8 (1.4)
Crossed eye	12 (2.1)	10 (1.7)	22 (3.8)
Poor Vision	73 (12.8)	133 (23.3)	206 (36.0)
Others	36 (6.3)	56 (9.8)	92 (16.1)
Missing	1 (0.2)	2 (0.3)	3 (0.5)

Parents and carers make the decision to visit the hospital and decision making becomes an important step towards accessing eye care services for the children (Glascoe, 2003). The decision making process is influenced by the cultural values in rural areas and in many families the male member of the family who is the earning member makes the decision (Balasubramaniam, 2013). In families where both parents are educated, then there will be a discussion before any decision which is made jointly. In this research, in almost half the cases both parents have made a joint decision to take the child to the hospital and the details of persons involved in decision making is presented in Table 4.10.

Table 4.8 Persons responsible for the decision to take the child to the eye hospital.

Relationship	Gender		Total
	Boys	Girls	
Father	37 (6.5)	36 (6.3)	73 (12.8)
Mother	60 (10.5)	45 (7.9)	105 (18.4)
Both parents	173 (30.2)	106 (18.5)	279 (48.8)
Elders at home	41 (7.2)	34 (5.9)	75 (13.1)
Others	25 (4.4)	15 (2.6)	40 (7.0)
Total	336 (58.8)	236 (41.2)	572 (100)

4.3.3 Mean age at recognition and at the surgery comparison

Mean age for childhood cataract surgery (excluding the traumatic cataract) was 74.6 months (SD 55.8; congenital 48.2 (SD 50.9); developmental 99.7 (SD 46.42). The mean age at surgery for bilateral congenital cataract was 47.7 months (SD 50.4) and for unilateral congenital cataract it was 51.9 months (SD 55.3). Similarly, 228 children had bilateral developmental cataract and the mean age at surgery was 97.3 (SD 46.2) months. 41 children presented with unilateral development cataract and the mean age at surgery was 113.2 (SD 46.1) months. The comparative data on age at recognition and their respective mean age at surgery by gender for both congenital and developmental cataract is shown in Table 4.11.

Table 4.9 Age at recognition and the mean age at surgery for Congenital and Developmental Cataract by gender

Age (in months) at which eye problem was recognized	Mean and age range for childhood cataract surgery (in months)											
	Congenital cataract						Developmental cataract					
	Boys			Girls			Boys			Girls		
	n (%)	Unilateral	Bilateral	n (%)	Unilateral	Bilateral	n (%)	Unilateral	Bilateral	n (%)	Unilateral	Bilateral
≤ 1	39 (23)	6.68 (5.0 – 8.6)	33.34 (1.2 – 144.0)	24 (19.7)	4.34 (2.2 – 8.6)	42.39 (2 -156.7)	5 (3.0)	156 (144 -168.0)	18.7 (6.0 – 39.1)	3 (2.6)	33.6 (33.6)	156.3 (144 – 168.5)
>1 - 6	48 (28.7)	8.19 (4.4 – 12.0)	19.11 (2.8 – 136.0)	44 (36.1)	8.01 (4.8 – 12.0)	19.69 (3.3 – 108)	12 (7.0)	102 (60 -144.0)	66.5 (3.6 – 168.0)	4 (3.5)	48 (48.0)	86.5 (36.0 – 139.6)
> 6 - 12	21 (12.6)	14.0 (10.0 – 18.0)	57.73 (4.7 – 180.0)	12 (9.8)	46.58 (11.9 – 108)	16.89 (9.5 – 48.0)	4 (2.4)	-	52.2 (12 – 120.0)	11 (9.6)	96.9 (96.9)	74.4 (21.9 – 152.3)
< 12	108 (64.9)	9.2 (4.4 -18.0)	31.4 (1.2 – 179.9)	80 (65.6)	19.6 (2.2 – 108)	26.1 (2.0 – 156.7)	21 (12.4)	129 (60 – 168)	54.6 (3.6 – 168)	18 (15.8)	59.4 (33.6 – 96.9)	74.487.7 (21.9 – 168.5)

Table 4.11 Age at recognition and the mean age at surgery for Congenital and Developmental Cataract by gender

Age (in months) at which eye problem	Mean and age range for childhood cataract surgery (in months)											
	Congenital cataract						Developmental cataract					
	Boys			Girls			Boys			Girls		
	n (%)	Unilateral	Bilateral	n (%)	Unilateral	Bilateral	n (%)	Unilateral	Bilateral	n (%)	Unilateral	Bilateral
>12 – 36	22 (13.2)	21.6 (19.2 – 24.0)	40.2 (13.4 – 96.0)	17 (13.9)	45.76 (24 – 84.0)	66.82 (24 – 155.5)	29 (17.2)	87.3 (30.6 – 144.0)	56.98 (19.2 – 120.0)	15 (13.2)	94.96 (33.9 – 156.0)	68.2 (31.2 – 192.0)
>36 –120	32 (19.2)	114.46 (96 – 144.0)	102.36 (58.7 – 198.7)	23 (18.9)	65.74 (37.1 – 94.4)	104.5 (39.7 – 167.3)	92 (54.4)	92.5 (48 – 144.0)	100.5 (48 – 194.5)	55 (48.2)	124.2 (60 – 180.0)	97.9 (39.5 – 180.0)
>120	5 (2.9)	141.31 (130.7 – 150.8)	168 (168.0 – 168.0)	2 (1.6)	178.7 (178.7- 178.7)	168 (168.0 – 168.0)	27 (15.9)	154.2 (132 – 180)	159.5 (132 – 192)	26 (22.8)	161.9 (132 – 180)	154.4 (125.9 – 192)
All cases	167 (100)	61.8 (4.4 – 150.8)	47.6 (1.2 – 199.0)	122 (100)	41.9 (2.2 – 178.7)	47.9 (2.0 – 168.0)	169 (100)	114.2 (30.6 – 180.0)	94.57 (3.6 – 194.5)	114 (100)	122.7 (33.6 – 180.0)	104.1 (21.9 – 192.0)

4.3.4 Mean age comparison

The mean age was significantly different between various socio economic and demographic factors including cataract type, laterality, region, place of birth, parental occupation, education and income and the details are given in Table 4.12.

Table 4.10 Comparison of socio economic status (SES) factors with the mean age at surgery for childhood cataract

SES Variable	Groups	Mean	SD	P value
Gender	Boys	73.6	54.6	0.601
	Girls	76.1	57.3	
Cataract Type	Congenital	48.2	50.9	<0.0001
	Developmental	101.6	46.9	
Laterality	Bilateral	71.9	54.8	<0.001
	Unilateral	90.9	59.5	
Location	Rural	76.9	55.7	0.02
	Urban	61.9	54.7	
Region	South West	52.8	51.4	<0.0001
	North East	95.4	51.7	
Treatment category	Non paying	79.8	55.5	0.03
	Paying	69.7	55.7	
Birth place	Hospital	58.5	52.5	<0.0001
	Home	108.5	46.6	
Parental consanguinity	Present	69.9	54.9	0.22
	Absent	76.3	56.0	
Family history of childhood cataract	Present	81.6	51.1	0.26
	Absent	73.6	56.4	
Mother’s occupation	Not working	71.4	53.7	0.02
	Working	84.3	60.7	
Father’s occupation	Daily labour	80.8	56.0	<0.0001
	All others	59.6	52.4	
Mother’s Education	No education	99.9	54.3	<0.0001
	Any education	60.6	51.5	

Father's Education	No education	97.4	55.8	<0.0001
	Any education	64.9	52.9	
Family Income	<INR 5000	89.6	53.3	<0.0001
	>INR 5001	62.5	54.8	

All those variables that were found to be significant as shown in Table 4.12 were considered for multivariate analysis. Further a multiple regression was run to predict factors associated with the age at childhood cataract surgery from birthplace, parental education, father's occupation, cataract type, residential location and region. These variables statistically predicted the age at surgery, F (10, 740) = 52.2, P<0.05, R2 = 0.41. Other than family income, father's occupation and residential location, the remaining variables added statistically significantly to the prediction, P <0.05, and the details are given in Table 4.13.

Table 4.13 Multivariate linear regression analysis on factors associated with the age at childhood cataract surgery

Variables	Co- efficient	P value	95% CI for B	
			Lower bound	Upper bound
Birthplace	20.3	<0.001	12.2	28.3
Treatment category	-10.1	<0.05	-17.1	-3.1
Cataract Type	46.2	<0.001	38.9	53.4
Family income	-2.5	0.48	-9.6	4.5
Mothers education	-11.1	<0.05	-19.0	-3.1
Fathers education	-15.1	<0.001	-23.3	-6.8
Fathers occupation	-3.6	0.39	-11.8	46
Location	3.7	0.44	-5.8	13.3
Laterality	11.2	<0.001	4.0	18.3
Region	10.8	<0.05	2.9	18.7

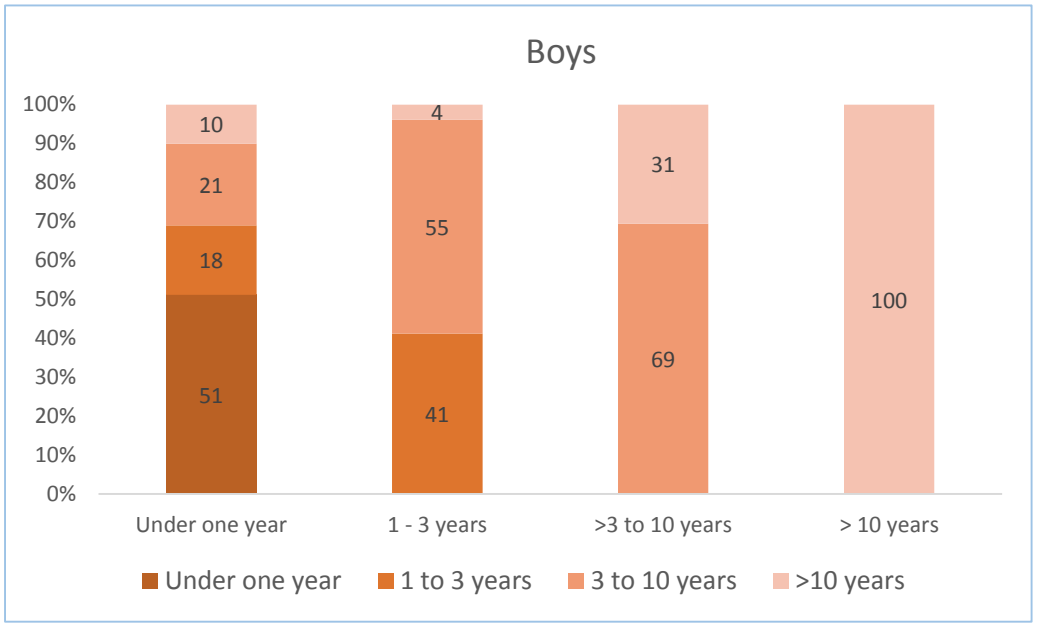
4.3.5 Age at recognition and at surgery comparison

Out of all childhood cataract recognized within one year, surgery took place within the same year in only 51% of cases. Figure 4.5 –4.7 shows the comparison of age at recognition and

the age at surgery for childhood cataract by gender, laterality and by cataract type. There was no significant difference found in the comparison of age at recognition and at surgery in these three categories. Figure 4.8 shows the overall comparison of age at recognition and the age at surgery for childhood cataract in India which highlights that there are delay for surgery after recognition of cataract in children.

Figure 4.5 Comparison of age at recognition and the age at the surgery for childhood cataract by gender.

(X axis indicates the age at recognition with the problem by the carers. Each column represents the proportion of children recognized during the time period and different colour indicates the time at which surgery was completed)



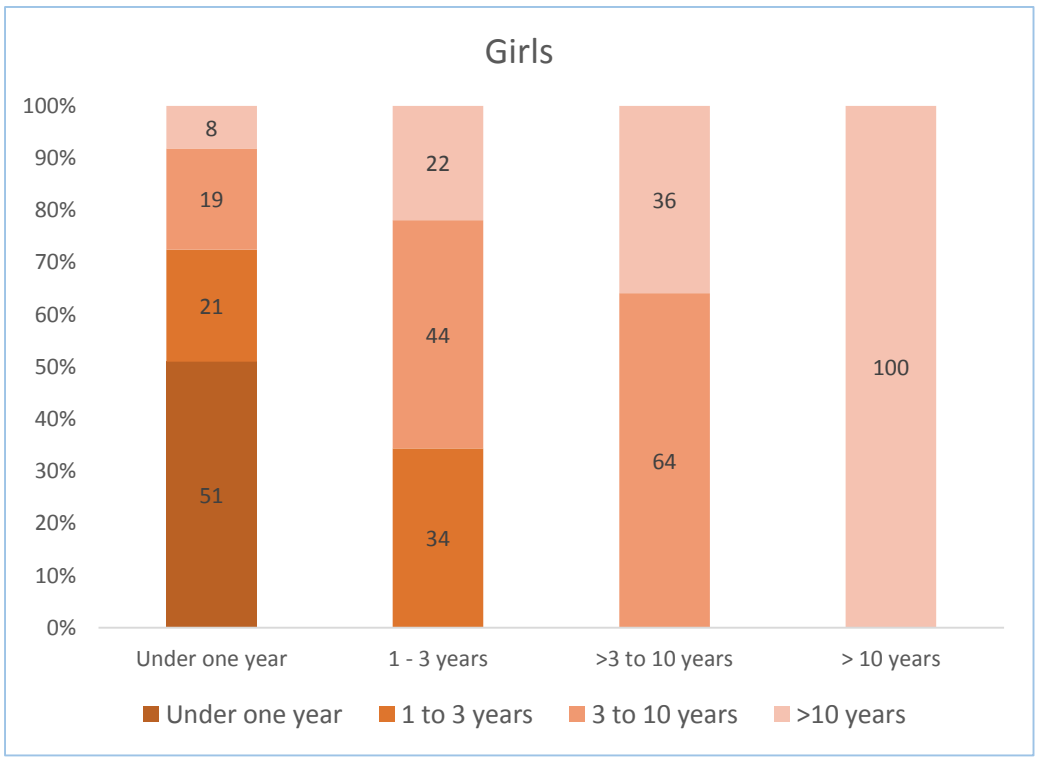
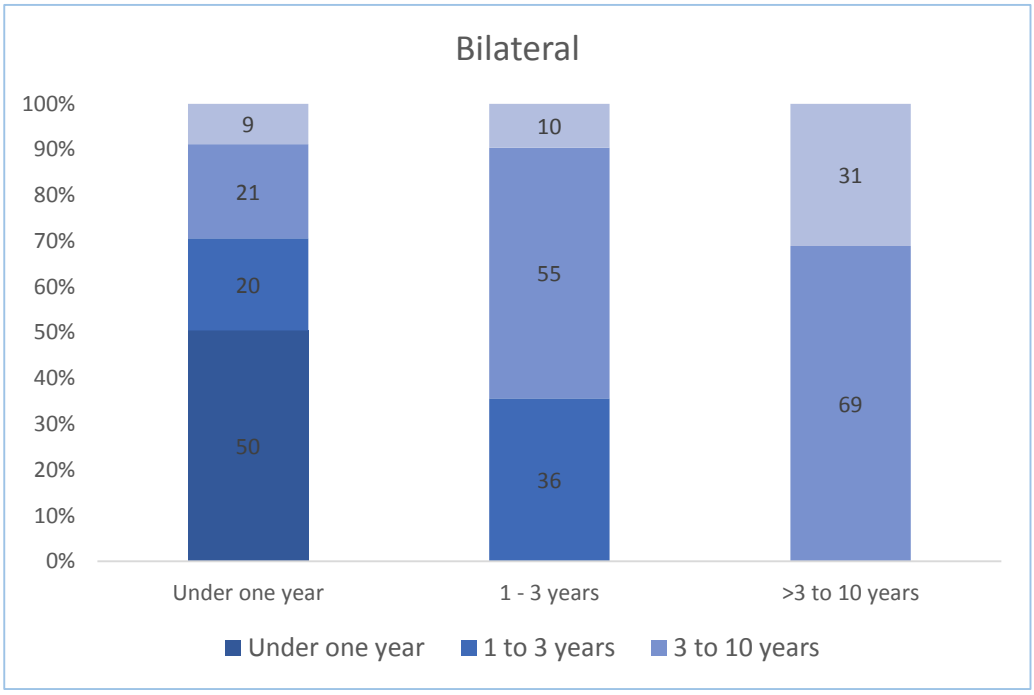


Figure 4.6 Comparison of age at recognition and the age at the surgery for childhood cataract by laterality.

(X axis indicates the age at recognition with the problem by the carers. Each column represents the proportion of children recognized during the time period and different colour indicates the time at which surgery was completed)



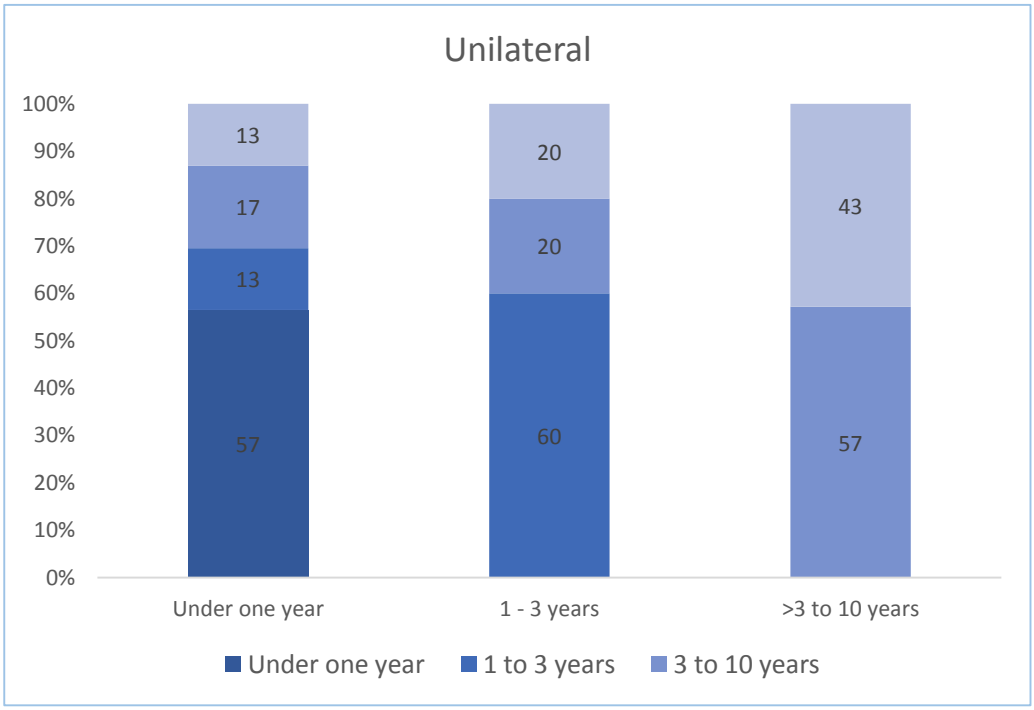
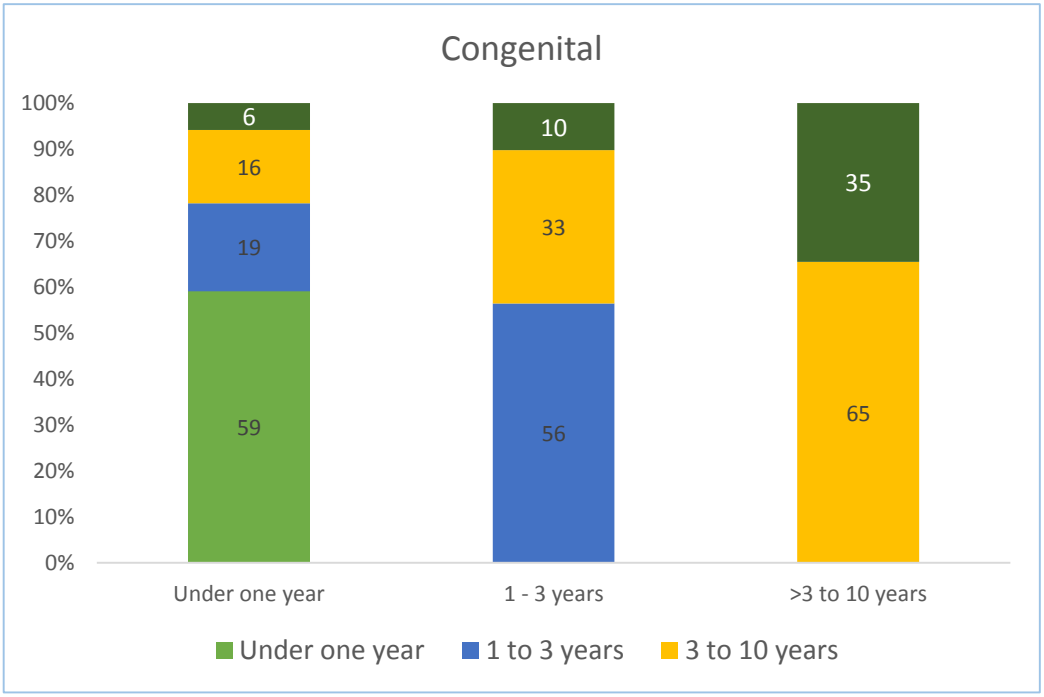


Figure 4.7 Comparison of age at recognition and the age at the surgery for childhood cataract by cataract type.

(X axis indicates the age at recognition with the problem by the carers. Each column represents the proportion of children recognized during the time period and different colour indicates the time at which surgery was completed)



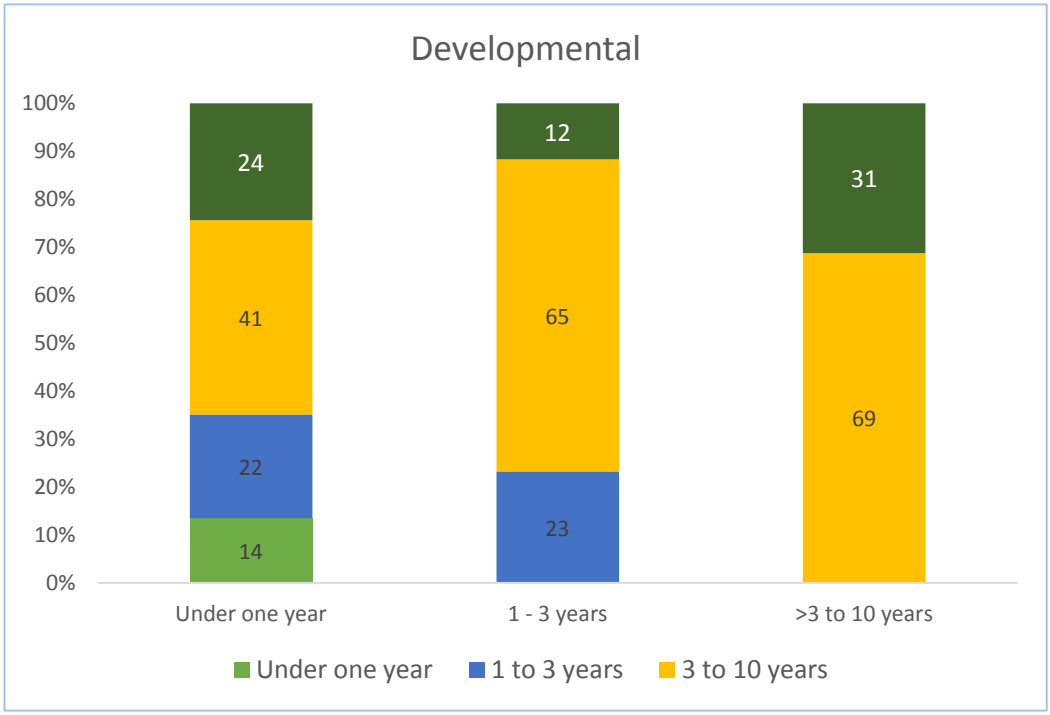
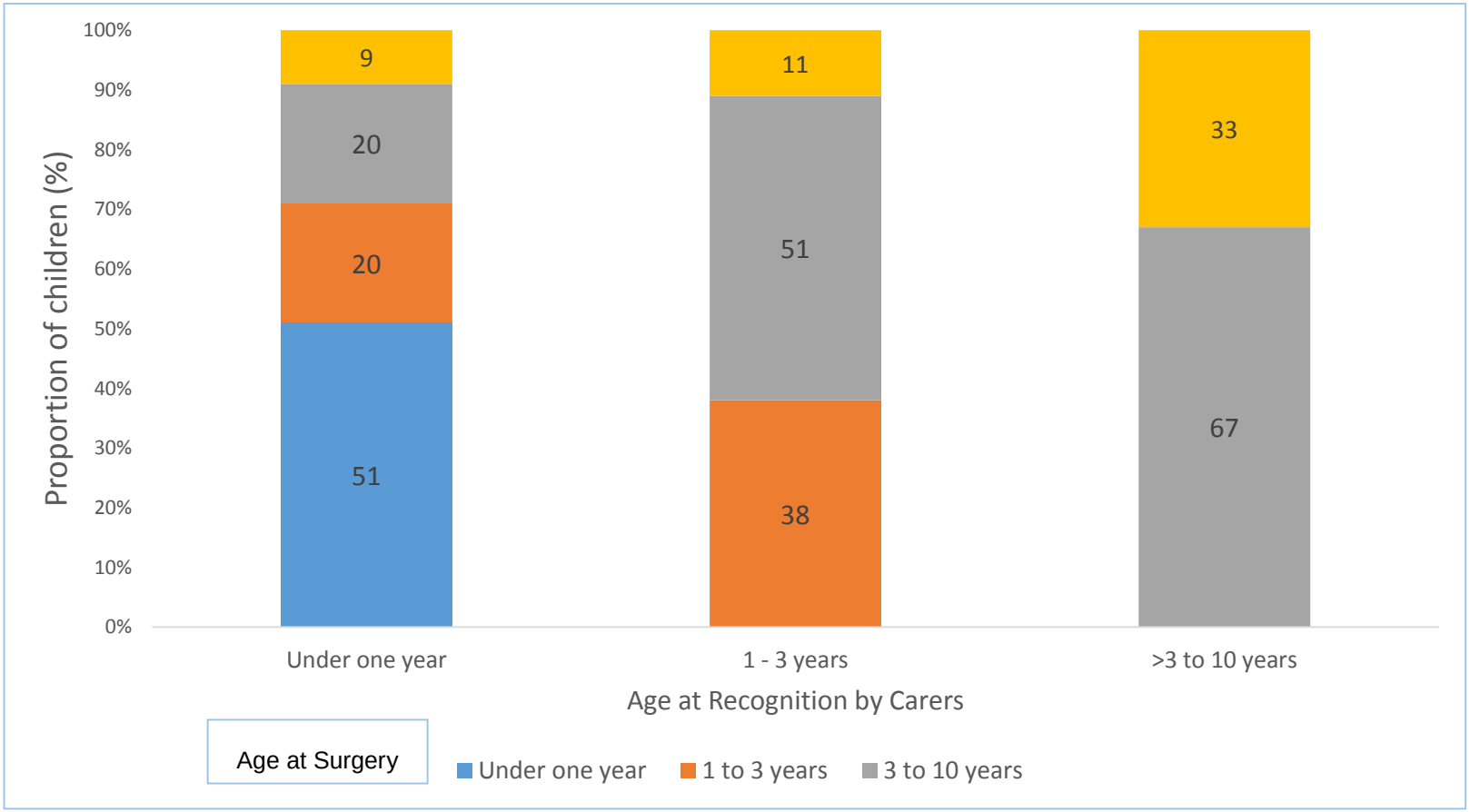


Figure 4.8 Comparison of age at recognition and the age at surgery for childhood cataract



4.4 Regional variation

The data were collected from different regions of the country and as described earlier in the methods section 2.11, the participating hospitals were grouped into five regions. The mean age for childhood cataract ranged from 51.61 to 89.26 months. The mean ages at surgery for congenital cataract in South, West, Central, North and Eastern regions were 32.4, 36.3, 60.5, 81.1 and 79.4 months, respectively, while the corresponding figures for developmental cataract were 83.4, 89.1, 108.2, 117.6 and 99.8 months (Figure 4.9).

There was a statistically significant difference between regions as determined by one way ANOVA ($F(4,567) = 25.08$, $p = <0.001$). A Tukey post hoc test revealed that the age at surgery for childhood cataract was statistically significantly lower in the Southern region compared to Central, North and Eastern regions. There was no statistically significant difference between the South and Western regions ($p = 0.79$). The mean age and standard error is presented in Figure 4.9 and mean age and standard deviation is presented in Table 4.13.

Figure 4.9 Mean age and the standard error of childhood cataract surgery across India

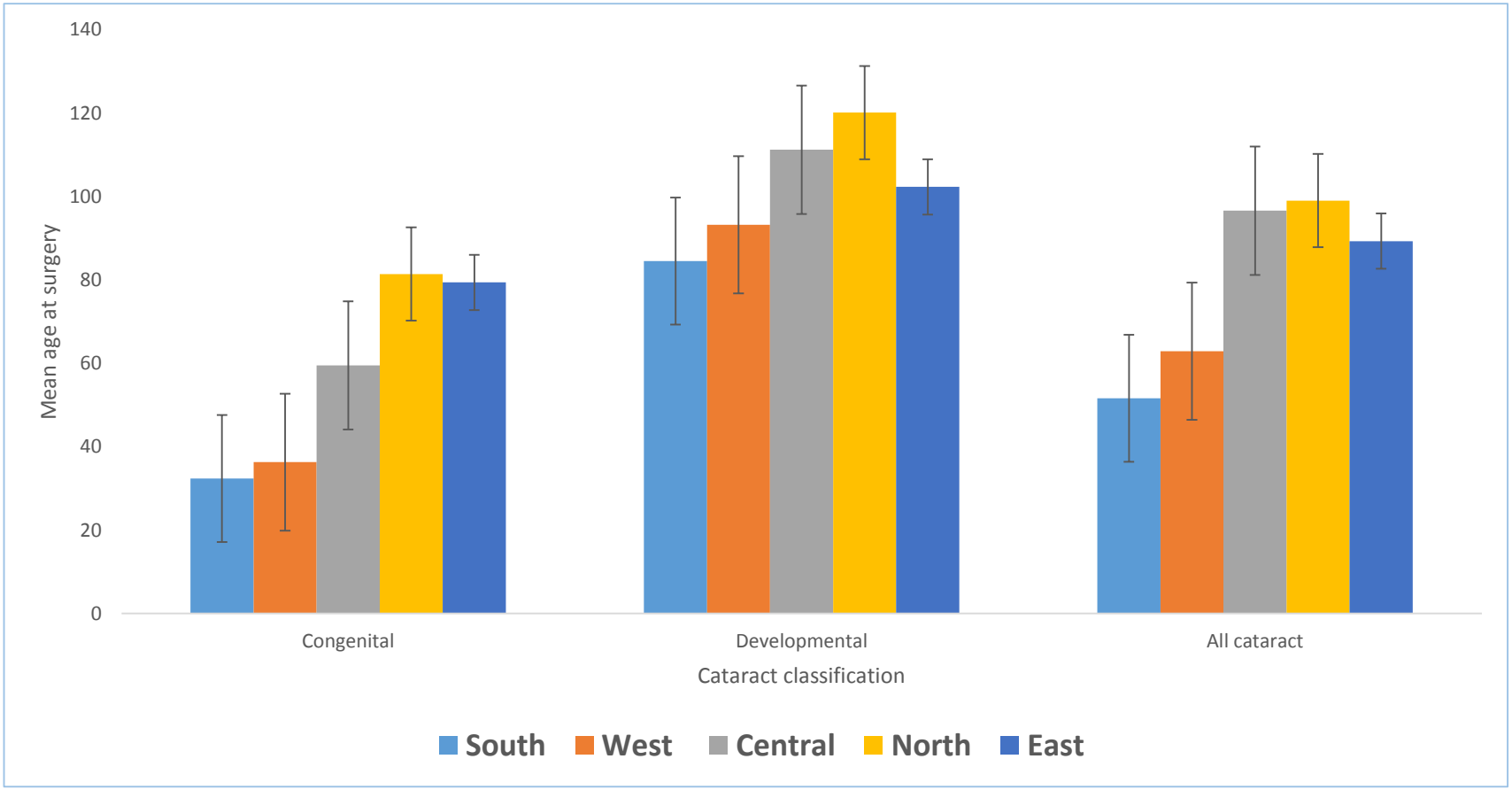


Table 4.11 Mean age (standard deviation) at surgery in different regions in India

Region	Congenital cataract	P value	Developmental cataract	P value	All childhood cataract	P value
South	32.4 ± 44.9	1	83.4 ± 46.6	Reference	51.6 ± 51.9	1
West	36.3 ± 28.8	0.73	89.1 ± 43.5	0.51	62.8 ± 46.4	0.26
Central	60.5 ± 48.8	<0.0001	111.2 ± 43.68	<0.0001	96.6 ± 50.7	<0.0001
North	81.1 ± 61.2	<0.0001	120.1 ± 47.7	<0.001	99.0 ± 58.3	<0.0001
East	79.4 (47.2)	<0.0001	102.3 (47.85)	0.08	89.3 (48.5)	<0.0001

4.4.1 Clinical findings

Cataract surgery was performed in the right eye for 304 (53.1%) cases and in the left eye for 266 (46.5%) of the cases. In 2 cases, both eyes were operated on the same day. Majority of the cataract was total (68.2%) and completely obstructing the light rays passing through the lens causing significant vision problems. But in these cases classification was based on the history of onset of the cataract as discussed earlier in the methods section.

Only one fifth of children (n=117, 20.4%) had cataract extraction without intra ocular lens (IOL) implantation and all remaining children (n=454, 80%) had surgery with IOL. All the children who did not have IOL implantation had to undergo secondary IOL implantation or continue with aphakic glasses or contact lenses. Around 44% of these aged less than 6 months had surgery without IOL implantation with similar proportions after 6 months of age, see Figure 4.10.

Figure 4.10 Proportion of children who did not have IOL implantation in different age groups

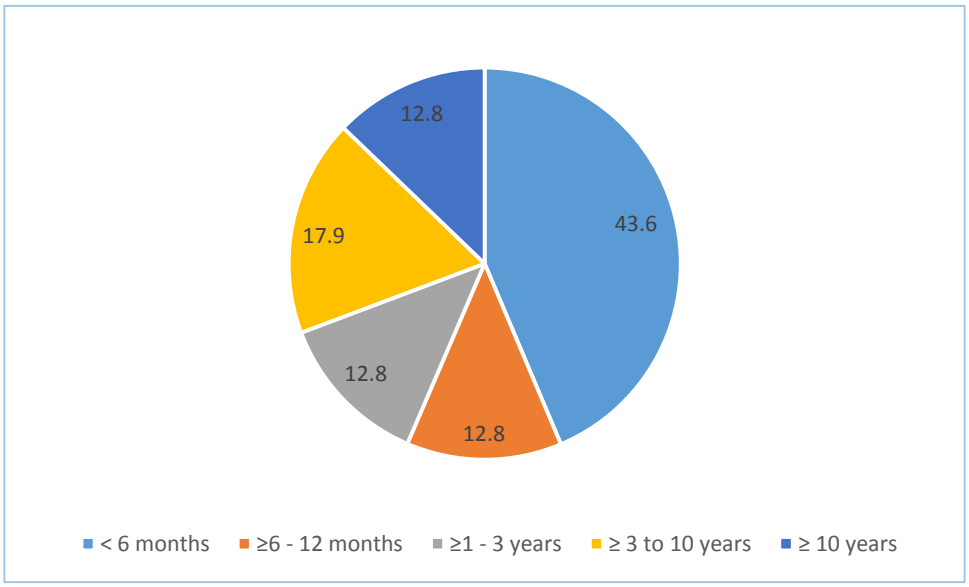


Table 4.12 Proportion of children completed cataract surgery with and without IOL at each centre

Centre name	Cataract surgery		
	With IOL	Without IOL	
		All cases	< 1 year of age
L V Prasad Eye Institute (LVPEI), Hyderabad, Telangana	112 (70)	49 (30)	33 (20.4)
L V Prasad Eye Institute (LVPEI), Vijayawada, Andhra Pradesh	28 (80)	7 (20)	5 (14.3)
L V Prasad Eye Institute (LVPEI), Visakhapatnam, Andhra Pradesh	18 (66.7)	9 (33.3)	7 (25.9)
Little Flower Hospital & Research Centre, Angamaly, Kerala	20 (74.1)	7 (25.9)	7(25.9)
PBMA's H V Desai Eye Hospital, Pune, Maharashtra	19 (63.3)	11 (36.7)	7 (23.3)
Dr. Shroff's Charity Eye Hospital, New Delhi	46 (83.6)	9 (16.4)	6 (10.9)
Sadguru Netra Chikitsalaya, Chitrakoot, Madhya Pradesh	159 (91.4)	15 (8.6)	2 (1.1)
Vivekananda Mission Ashram, Netra Niramaya Niketan, Haldia, West Bengal	37 (90.2)	4 (9.8)	1 (2.4)
Sri Sankaradeva Nethralaya, Guwahati, Assam	15 (68.2)	7 (31.8)	4 (18.2)
All centres (Total)	454 (79.4)	118 (20.6)	72 (61.0)

Table 4.14 shows the proportion of children operated with and without IOL implantation for their childhood cataract in each centre. The decision to implant an IOL depends on the operating surgeon in each hospital. Of the total number of children who had no IOL implantation (n=118), 61% of them were below one year of age.

Other Eye Problems

Among the congenital and developmental cataract cases, the most commonly diagnosed other eye problem was nystagmus (n=86; 41%) and the details of other ocular and systemic morbidities are presented in Table 4.15.

Table 4.13 Proportion of comorbidities presented at the time of surgery

Details of comorbidities	n (%)
Nystagmus	86 (40.8)
Exotropia	27 (12.8)
Micro cornea / micropthalmos	24 (11.4)
Systemic diseases	33 (15.6)
Amblyopia	5 (2.4)
Emmetropia	1 (0.5)
Other eye problems	35 (16.6)

Details of disability among the participants

Thirty nine (7%) children had other disabilities at the time of surgery and 14 (2.4%) children presented with syndromes. Of the fourteen children, 8 had Down syndrome, 2 each with Marfens and rubella syndrome and 1 child with Lowes syndrome. The details of disability is given below.

Disability details	**n (%)**
Delayed milestone	29 (64.4)
Intellectual disability	6 (13.3)
Physical deformity	2 (4.4)
Others	8 (17.8)
Total	45 (100)

The disability and the syndromes were analysed by gender and there was no significant difference in the frequency of other eye conditions or disability by gender among the study participants (p = 0.65).

4.4.2 Factors associated with the delay in accessing surgery

From the results, it was evident that across India there exists a delayed presentation for childhood cataract surgery. In this section, the socio demographic factors associated with the delay in accessing the childhood cataract surgery are presented. Two different analyses were used.

1. All congenital and developmental cataracts were grouped together. Considering age at surgery as an outcome factor, data was further grouped into four categories as (1) <12 months (2) >12 – 36 months (3) >36 to 120 and (4) >120 months.
2. The association for delayed surgery was analysed only for congenital cataract cases. The delay was defined as > 12 months for surgery in these cases. Both univariate and multivariate regression analyses were performed.

Childhood cataract (both congenital and developmental)

In the univariate analysis, for children operated within 12 months, religion, parental education and age, number of siblings at home and families with income >INR 5000 per month (approximately £60 per month) were associated significantly with early presentation. Table 4.16 shows the association of various factors with the different age at presentation for cataract surgery in children. All those factors which are found to be significant are highlighted in red colour in the respective table. In the multivariate model, a few factors were found to be significant. Most importantly, the families with more than one child had a higher chance of presenting early for surgery; in families with 2 to 4 children (OR, 75.0; 95% CI: 13.9 – 404.5; p = <0.001) and in families with five and more children (OR, 4.54; 95% CI: 1.10 – 18.72; p = 0.04). Table 4.17 shows the results of Multivariate analysis for the various factors associated with cataract surgery in different age groups.

Table 4.14 Univariate Logistic regression analysis of underlying factors associated with presentation age for cataract surgery

Factors	Within ≤ 12 months n= 116		>12 to 36 months n= 76		> 36 to 120 months n = 224		>120 months n = 156	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Gender (Boys vs Girls)	0.91 (0.60 – 1.37)	0.65	1.04 (0.64 – 1.69)	0.87	0.75 (0.53 – 1.06)	0.10	1.27 (0.88 – 1.84)	0.21
Location (Rural Vs Urban)	0.78 (0.45 – 1.34)	0.36	1.73 (0.95 – 3.13)	0.07	0.92 (0.58 – 1.47)	0.73	0.59 (0.34 – 1.05)	0.07
Treatment category (Paying Vs Non-paying)	0.72 (0.48 – 1.09)	0.12	1.07 (0.66 – 1.73)	0.79	0.98 (0.69 – 1.37)	0.89	0.76 (0.52 – 1.09)	0.14
Religion (Hindu Vs Other religion)	0.51 (0.32 – 0.82)	<0.001	1.44 (0.81 – 2.56)	0.22	0.80 (0.51 – 1.24)	0.32	0.52 (0.31 – 0.89)	<0.01
Father's education (No education Vs Any education)	0.39 (0.23 – 0.67)	<0.001	1.55 (0.87 – 2.74)	0.13	1.22 (0.84 – 1.77)	0.29	0.35 (0.24 – 0.51)	<0.001
Mother's education (No education Vs Any education)	0.35 (0.21 – 0.58)	<0.001	2.75 (1.49 – 5.05)	<0.001	1.06 (0.75 – 1.51)	0.74	0.28 (0.19 – 0.41)	<0.001
Family history with Childhood Cataract	1.61 (0.79 – 3.24)	0.19	2.14 (0.83 – 5.50)	0.11	0.60 (0.37 – 0.99)	<0.05	0.93 (0.53 – 1.62)	0.76

Table 4.16 Univariate Logistic regression analysis of underlying factors associated with presentation age for cataract surgery

Factors	Within ≤ 12 months n= 116		>12 to 36 months n= 76		> 36 to 120 months n = 224		>120 months n = 156	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Child's birth order								
1st child		-						
2nd – 4th child	4.83 (0.63 – 36.9)	0.13	0.96 (0.21 – 4.41)	0.96	0.76 (0.29 – 1.94)	0.57	0.67 (0.25 – 1.77)	0.42
5th and above	4.65 (0.61 – 35.5)	0.14	1.61 (0.36 – 7.21)	0.53	0.67 (0.26 – 1.69)	0.39	0.60 (0.23 – 1.59)	0.31
No of siblings								
Only child		-						
2 – 4 children	53.8 (15.4 – 187.9)	<0.001	3.69 (1.09 – 12.5)	0.04	0.55 (0.27 – 1.10)	0.09	0.000	0.997
5 & above	6.8 (2.09 – 22.0)	<0.001	4.36 (1.55 – 12.3)	<0.001	1.29 (0.82 – 2.03)	0.28	0.25 (0.16 – 0.39)	<0.001
Parental consanguinity	1.36 (0.87 – 2.11)	0.18	1.04 (0.59 – 1.79)	0.89	0.87 (0.59 – 1.27)	0.48	1.53 (0.99 – 2.37)	0.06
Father's age (<30 years vs >30 years)	0.27 (0.18 – 0.41)	<0.001	0.41 (0.25 – 0.67)	<0.001	1.12 (0.79 – 1.61)	0.55	9.20 (4.84 – 17.51)	<0.001
Mother's age (<30 years vs > 30 years)	0.21 (0.12 – 0.35)	<0.001	0.19 (0.09 - 0.39)	<0.001	0.91 (0.64 – 1.28)	0.59	7.13 (4.72 – 10.78)	<0.001

Table 4.16 Univariate Logistic regression analysis of underlying factors associated with presentation age for cataract surgery

Factors	Within ≤ 12 months n= 116		>12 to 36 months n= 76		> 36 to 120 months n = 224		>120 months n = 156	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Laterality (Bilateral vs Unilateral)	1.34 (0.71 – 2.53)	0.36	0.82 (0.39 – 1.71)	0.59	0.56 (0.33 – 0.94)	0.03	2.45 (1.50 – 3.99)	<0.001
Family's reported income (£1 = INR 83)								
< INR 5000								
INR5001 – INR 20000	0.32 (0.15 – 0.71)	<0.001	0.69 (0.28 -1.69)	0.42	1.21 (0.61 – 2.39)	0.59	2.31 (1.03 – 5.22)	0.043
>INR20001	1.08 (0.52 – 2.26)	0.84	0.76 (0.31 – 1.82)	0.53	1.05 (0.53 – 2.08)	0.88	1.06 (0.46 – 2.41)	0.899

Table 4.15 Multivariate Logistic regression analysis of underlying factors associated with presentation age for cataract surgery

Factors	Within ≤ 12 months n= 116		>12 to 36 months n= 76		> 36 to 120 months n = 224		>120 months n = 156	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Gender (Boys vs Girls)	0.84 (0.48 – 1.48)	0.55	0.88 (0.52 – 1.51)	0.65	1.29 (0.89 – 1.88)	0.17	1.08 (0.67 – 1.75)	0.74
Location (Rural Vs Urban)	1.65 (0.78 – 3.48)	0.19	0.69 (0.35 – 1.36)	0.23	1.04 (0.62 – 1.76)	0.88	1.12 (0.55 – 2.27)	0.76
Treatment category (Paying Vs Non-paying)	0.68 (0.36 – 1.30)	0.24	0.95 (0.52 – 1.73)	0.99	1.17 (0.78 – 1.77)	0.45	1.50 (0.87 – 2.60)	0.15
Religion (Hindu Vs Other religion)	0.73 (0.38 -1.40)	0.34	0.83 (0.44 – 1.57)	0.56	0.98 (0.60 – 1.58)	0.92	1.36 (0.70 – 2.64)	0.36
Father's education (No education Vs Any education)	0.55 (0.24 – 1.25)	0.15	1.19 (0.54 – 2.59)	0.67	0.73 (0.45 – 1.20)	0.22	1.97 (1.08 – 3.59)	0.03
Mother's education (No education Vs Any education)	0.78 (0.35 -1.75)	0.55	0.52 (0.24 – 1.15)	0.09	0.99 (0.62 – 1.58)	0.95	1.36 (0.77 – 2.41)	0.29

Table 4.17 Multivariate Logistic regression analysis of underlying factors associated with presentation age for cataract surgery

Factors	Within ≤ 12 months n= 116		>12 to 36 months n= 76		> 36 to 120 months n = 224		>120 months n = 156	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Family history with Childhood Cataract	0.73 (0.29 -1.84)	0.50	0.49 (0.18 – 1.34)	0.21	2.03 (1.16 – 3.57)	0.01	0.69 (0.33 – 1.42)	0.31
Child's birth order								
1st child		-		-		-		-
2nd – 4th child	0.07 (0.01 – 1.02)	0.05	0.11 (0.02 – 0.75)	0.02	0.71 (0.24 – 2.12)	0.54	8.95 (2.63 – 30.4)	<0.001
5th and above	0.35 (0.03 – 4.28)	0.41	0.23 (0.04 – 1.49)	0.16	0.58 (0.20 -1.65)	0.31	3.24 (1.04 – 10.13)	0.043
No of siblings								
Only child		-		-		-		-
2 – 4 children	75.0 (13.9 – 404.5)	<0.001	2.41 (0.48 – 11.98)	0.15	0.60 (0.25 – 1.47)	0.27	0.000	0.99
5 & above	4.54 (1.10 – 18.72)	0.04	2.77 (0.76 – 10.09)	0.09	1.44 (0.82 – 2.52)	0.21	0.37 (0.19 – 0.68)	<0.001
Parental consanguinity	0.88 (0.46 – 1.69)	0.69	0.84 (0.45 – 1.57)	0.58	1.07 (0.69 – 1.66)	0.76	0.96 (0.53 – 1.73)	0.89
Father's age (<30 years vs >30 years)	1.65 (0.85 – 3.2)	0.14	1.22 (0.66 – 2.25)	0.53	0.95 (0.59 – 1.53)	0.83	0.29 (0.13 – 0.63)	<0.001

Table 4.17 Multivariate Logistic regression analysis of underlying factors associated with presentation age for cataract surgery

Factors	Within ≤ 12 months n= 116		>12 to 36 months n= 76		> 36 to 120 months n = 224		>120 months n = 156	
	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Mother's age (<30 years vs > 30 years)	1.83 (0.84 – 3.96)	0.13	3.83 (1.69 – 8.67)	0.001	1.43 (0.90 – 2.28)	0.13	0.29 (0.17 – 0.52)	0.000
Laterality (Bilateral vs Unilateral)	1.33 (0.55 – 3.19)	0.52	1.33 (0.59 – 3.03)	0.49	1.96 (1.12 – 3.42)	0.02	0.37 (0.19 – 0.72)	0.004
Family's reported income (£1 = INR 83)								
< INR 5000		-	-	-		-		-
INR5001 – INR 20000	0.40 (0.13 -1.25)	0.12	1.01 (0.35 – 2.95)	0.98	1.15 (0.53 – 2.49)	0.73	1.39 (0.49 – 3.88)	0.53
>INR20001	0.88 (0.30 -2.5)	0.81	0.68 (0.24 – 1.88)	0.46	1.17 (0.55 – 2.50)	0.68	1.22 (0.44 – 3.42)	0.69

Congenital cataract only

In the univariate regression model, the age at presentation for late surgery (more than 12 months) among the congenital cataract cases had statistical correlation with location, region, parents' education and age, number of siblings at home, family's reported monthly income and with father's occupation (all p = <0.01). In the multivariate model, only two factors region and the number of siblings, were associated significantly with late surgery. Children with two and more siblings at home were almost five times more likely to undergo surgery within 12 months of age (OR, 4.69; 95% CI: 2.04 – 10.79; p = <0.001) and children from the North and Eastern region were more delayed in compared to their counterparts from South and Western regions (OR, 0.52; 95% CI: 0.27 - 0.97; p = <0.05), (Table 4.18).

Table 4.16 Multivariate Logistic regression analysis of underlying factors associated with surgery later than 12 months for congenital cataract

Factors	Univariate		Multivariate	
	OR (95% CI)	p value	OR (95% CI)	p value
Gender (Boys vs Girls)	0.83 (0.51 – 1.34)	0.44	1.38 (0.77 – 2.45)	0.28
Location (Rural Vs Urban)	1.31 (0.69 – 2.44)	0.41	1.26 (0.58 – 2.75)	0.56
Region (South & West vs North & East)	3.27 (1.93 – 5.55)	<0.001	0.52 (0.27 – 0.97)	0.04
Treatment category (Paying vs Non-paying)	2.37 (1.46 – 3.85)	<0.001	0.68 (0.34 – 1.33)	0.26
Laterality (Bilateral vs Unilateral)	1.11 (0.53 – 2.35)	0.79	0.96 (0.39 – 2.33)	0.96
Family history with Childhood Cataract	1.97 (0.92 – 4.21)	0.08	0.83 (0.32 – 2.17)	0.70
Parental consanguinity	1.16 (0.69 – 1.94)	0.56	0.94 (0.49 – 1.83)	0.87
Father's age (<30 years vs >30 years)	2.92 (1.79 – 4.78)	<0.001	0.55 (0.28 – 1.08)	0.08

Mother's age (<30 years vs > 30 years)	3.25 (1.76 – 6.00)	<0.001	0.65 (0.29 – 1.43)	0.28
Father's education (No education vs Any education)	3.29 (1.85 – 5.86)	<0.001	0.59 (0.27 – 1.34)	0.21
Mother's education (No education vs Any education)	2.71 (1.55 – 4.76)	0.001	0.70 (0.32 – 1.54)	0.37
Father's occupation (Labourers vs All others)	2.25 (1.34 – 3.79)	0.002	0.72 (0.34 – 1.54)	0.39
Mother's Occupation (Not working vs working)	1.15 (0.69 – 1.92)	0.60	0.90 (0.41 – 1.99)	0.80
No of siblings (Only child vs 2 or more)	8.55 (4.15 – 17.6)	<0.001	4.69 (2.04 – 10.79)	<0.001
Family's reported income (< INR 5000 vs > INR5001)	2.86 (1.68 – 4.85)	<0.001	0.55 (0.27 – 1.14)	0.11

4.4.3 Traumatic cataract

Mean age of the participants was 113.2 (SD: 45.3) months and it ranged from 7.2 months to 200. 5 months. The majority of the participants were boys (n = 133, 74%) and from rural areas (n = 159, 89%). The various socio demographic details of the study participants are presented in Table 4.19. Of the total 179 cases, 96 (53.6%) of the subjects had injury in right eyes and the remaining had left eye injury. 147 (82.1%) of them presented with total cataract and in others it was classified as partial cataract. The majority of the children received intra ocular lens implantation (n=148; 82.7%).

Table 4.17 Socio demographic details of the children presented with traumatic cataract

Variables	Total n (%)
Gender	
Boys	133 (74.3)
Girls	46 (25.7)
Treatment category	
Paying	121 (67.6)
Non paying	58 (32.4)
Residential location	
Urban	20 (11.2)
Rural	159 (88.8)
Region	
South India	43 (24.0)
Central India	93 (52.0)
West India	8 (4.5)
North India	16 (8.9)
East India	19 (10.6)
Father’s education	
No education	62 (34.6)
School education	103 (57.5)
University education	14 (7.8)
Mother’s education	
No education	93 (52.0)
School education	76 (42.5)
University education	10 (5.6)
Father’s occupation	
Daily Labourer	142 (79.3)
Formal employment (government / private	23 (12.8)
sector)	14 (7.8)
Others	

Variables	Total n (%)
Mother's occupation	
Not working	132 (73.7)
Daily Labourer	41 (22.9)
Formal employment (government / private sector)	6 (3.4)
Family's reported monthly income	
< INR 5000	97 (54.2)
INR 5001- INR 20,000	77 (43.0)
>INR 20,001	5 (2.8)

Only two infants presented with cataract after an eye injury and higher proportion of children was seen in the age group between 3 years and more (Table 4.20).

Table 4.18 Age distribution of children with traumatic cataract by gender

Age	Gender		Total
	Boys	Girls	
< 1 year	2 (1.2)	0 (0)	2 (1.2)
≥ 1 year to 3 years	8 (4.5)	1 (0.6)	9 (5.0)
≥ 3 to 10 years	55 (30.7)	24 (13.4)	79 (44.1)
≥ 10 years	68 (51.1)	21 (45.7)	89 (49.7)
Total	133 (74.3)	46 (25.7)	179 (100)

Of the total 179 cases, the details of the injury type were mentioned in the medical records for 107 (60%) cases and the injury details are presented in Table 4.21.

Table 4.19 Classification of injuries in children

Type of injuries	n
Wooden stick	45
Crackers	11
Iron rod	11
Pen/pencil/ cutter	8
Bow & arrow playing kit	4
Cricket ball	7
Blunt / penetrating injuries	7
Needle injury	4
Finger / nails	3
Insect bite / bird hit	2
Others	5
No details on the type of injuries	72
Total	179

4.5 Discussion

Overall, mean age at surgery for congenital cataract was 4 years and for the developmental cataract it was 8 years. More than two thirds of the congenital cataracts were recognized within one year from birth, which is a very positive finding. Around half of all cataracts were recognized by family members and in 40% of the cases it was by a parent.

The mean age at surgery was lower in South and Western regions of the country. Compared to this, the mean age was 2 times higher in Central region and 2.5 times higher in North and Eastern regions of the country. The disparities in health care within the country are well known, with some of the states in Southern and Western regions having better health indices compared to Northern regions (Bhandari, 2012).

Around half of all congenital cataracts are operated in the Southern region in this study. It may be due to the availability of specialist centres in Southern region and especially, the hospital which operated more number of congenital cataracts in this project is one of the advanced tertiary centre (www.lvpei.org) which receives referrals from all over the country. Additional possible factors are the more widespread community screening programs and the

higher transport accessibility in the Southern region than in the North and Eastern regions. In all the regions, unilateral cataract is operated less compared to the bilateral cataract.

Gender imbalance

No gender disparity in the prevalence of childhood cataract is reported in the literature (Sheeladevi et al., 2016). However in the current study, twice as many boys presented for surgery than girls, which is similar to previous reports (Courtright et al., 2008, Khandekar et al., 2007, Gilbert and Lepvrier-Chomette, 2016). Although there is an absolute number difference in utilisation by gender, the difference was not statistically significant. As discussed on page 47, it is possible that the sample size calculated for this study was not powered to detect the presence of gender as a risk factor, and this research could not clearly demonstrate this association. Confounding variables can influence both dependent and independent variables and can cause erroneous association (Vandenbroucke, 2002). The potential confounders need to be identified and necessary adjustment should be made during the study design stage. Confounders may be minimised with strategies such as randomization and matching and control of samples considered for the study. If it is not possible to adjust the study design for confounders their impact may be minimised during the analysis stage through stratification, standardization or through multivariate analysis (Kahlert et al., 2017).

However, the gender gap in utilization of the cataract surgical services by region was also examined and a similar pattern was observed in each region. This is supported by the published evidence from India that boys are much more likely than girls to undergo hospital based treatment, particularly in economically poor families (Asfaw et al., 2010). This is a major issue that needs further exploratory research to understand the reasons for differences in utilization.

Comparison of results with previously published studies

Overall, half of all cataract surgeries in this study occurred more than 12 months from birth and similar findings have been reported from a retrospective study from India (Gogate et al., 2010). The proportion of children undergoing surgery within 6 months was lower (16%) in the current study than has been reported in China (28%) (You et al., 2011). Similarly, the mean age at surgery for congenital cataract (27.6 (Lin et al., 2014) versus 48.2 months) and for all

childhood cataract (53.0 (Khanna et al., 2013) versus 74.6 months) were higher in the current study. Even though more than two thirds of cases were recognized within one year, these findings indicate that there are impediments to early surgery. These factors need to be explored in detail to reduce this disparity.

Similar to previous reports, in this study school teachers recognised 10% of cataract in older children confirms that, school teachers play a major role in identifying obvious eye defects in school aged children including visible cataract in India. In India, as part of the National program for control of blindness, School eye health screening program has been in place for more than two decades (Jose and Sachdeva, 2009). Millions of children have been screened every year and this program is found to be cost effective in screening for refractive errors and identifying obvious eye problems in children in India. Added advantage of this program is the huge volunteering support from the school teachers making it a cost effective strategy of school children eye screening in India (Limburg et al., 1995).

4.5.1 Importance of early surgery

Early treatment of childhood bilateral and unilateral cataract is important as untreated cataract in young children will cause dense amblyopia, particularly so in unilateral cases. Untreated bilateral cataract by causing visual disability has more impact on general development, including educational (Kulp and Schmidt, 1996) and social aspects. Although unilateral cataract allows vision with the unaffected eye but may cause amblyopia, and if untreated cataract impedes visual development and has long term impact on binocularity and risk of vision loss (Lloyd et al., 1995). Further, it has been shown that early surgery improves the outcomes in both unilateral and bilateral cataracts (Lambert and Drack, 1996, Lambert et al., 2006). It has been previously reported that congenital cataract operated after one year was associated with poorer visual outcomes (Khanna et al., 2013) and in the current study 40% of all congenital cataracts underwent surgery more than 3 years from birth. It would be of interest to study the long term visual outcomes in these cases, as cataract surgery is just the beginning of a long term visual rehabilitation in children. To achieve good visual outcomes, not only cataract removal but refractive correction and treatment of any amblyopia are also essential.

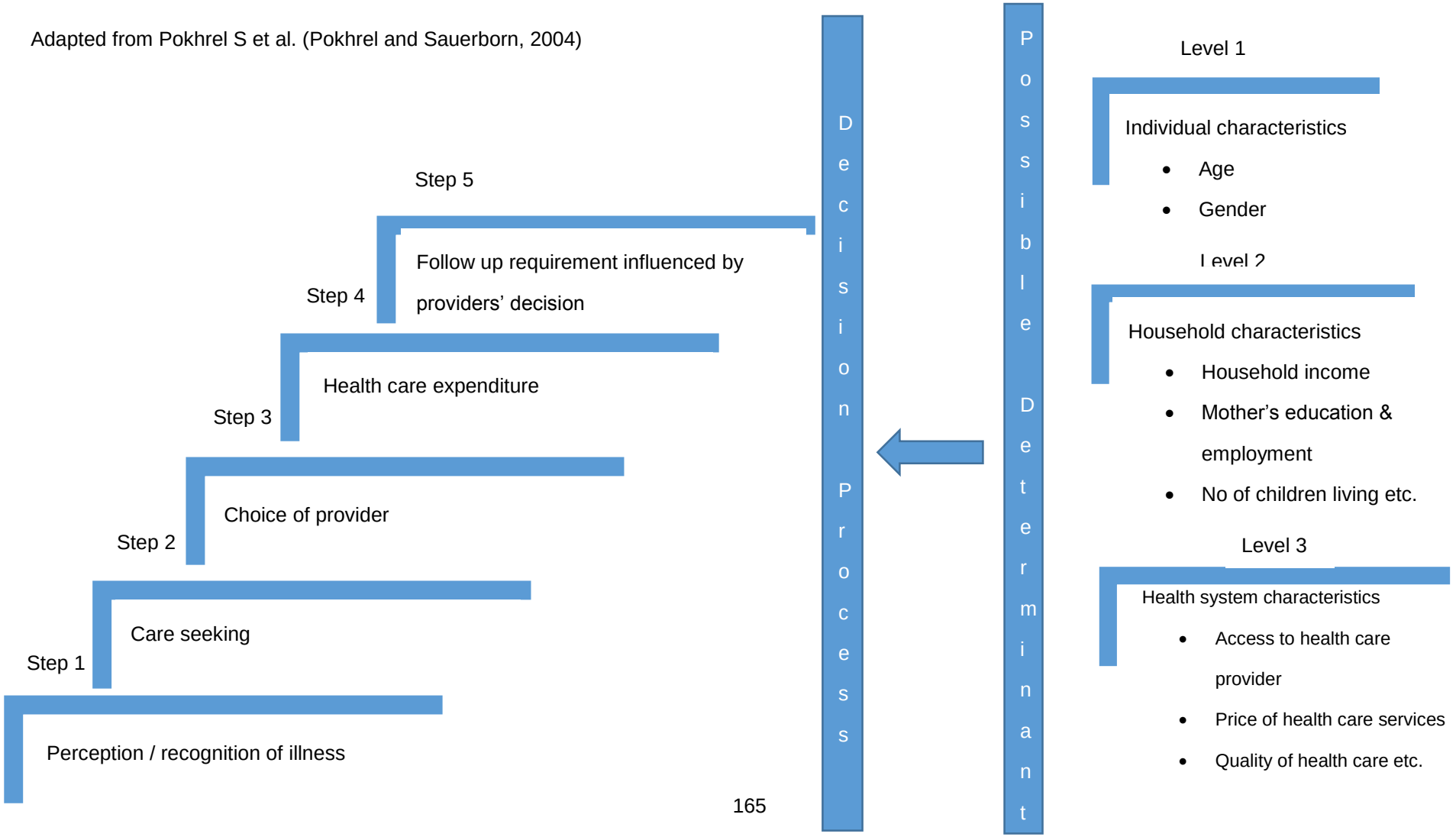
The previously reported prevalence of both unilateral and bilateral cataract was similar (Sheeladevi et al., 2016, Wu et al., 2016). However, in the current study 86% of the children

presented with bilateral cataract and only 14% presented with unilateral cataract suggesting that the majority of the children with unilateral cataract (both congenital and developmental) had not yet presented for surgery. This is an important finding since it suggests a low rate of presentation of unilateral cataract, with high risk of impaired visual development.

The differences highlighted here, including gender at presentation, laterality and regional delay in accessing childhood cataract services need to be bridged to achieve equitable access to health care, which is considered crucial for reaching many of the Sustainable Development Goals. (http://www.un.org/sustainabledevelopment/)

Figure 4.11 Socio demographic factors determining the decision-making process for childhood cataract services

Adapted from Pokhrel S et al. (Pokhrel and Sauerborn, 2004)



4.5.2 Uncertainty in childhood cataract definition

Various definitions of childhood cataract are used in the literature, introducing considerable uncertainty. One widely used definition is the age at onset: a congenital or infantile cataract presents within the first year of life, whereas cataract presenting between 1 and 10 years of life is classified as developmental or juvenile cataract (Hejtmancik, 2008). However, since the age of onset is generally unknown, previous studies on the factors affecting access to cataract surgery or vision impairment due to childhood cataract have adopted a pragmatic definition of childhood cataract. For example, previous studies (Mwende et al., 2005, You et al., 2011, Medsinge and Nischal, 2015) have defined congenital cataracts as those recognized by carers or which presented at the hospital when the child was below the age of one year. All those recognized after 12 months and not due to trauma were defined as developmental cataract. This method of categorization is widely used but it is problematic since a congenital cataract may not be recognized or reported for some time, but it still represents a congenital cataract. Therefore this approach would categorise such cases incorrectly. Moreover, as outlined earlier, childhood cataract that appears to not be congenital (not apparent at or within a certain time window after birth) is generally categorized as developmental, but the distinction between these two types is unclear. Clarity in defining and determining the time to surgery in childhood cataracts is essential in the future to address any access issues in these cases.

The present study used the clinicians' decision to categorize the cataract as congenital and developmental based on a common set of criteria across the study centres. If we assume all congenital cataract categorized by the clinicians are truly congenital (from birth), only one third of the unilateral congenital cataract cases completed surgery within one year and only one fifth of all congenital cataracts were surgically treated within one year with the remaining 80% treated later, from 1 to 10 years. In about half of the cases, the cataract was recognized by a parent or carers, so in these cases any delay was not caused by lack of parental awareness, instead, other factors such as accessibility to the surgical centres may be responsible. In the remaining half of the cases a parent or carer did not identify the cataract, indicating a lack of awareness of the condition and /or its significance.

It was significant to note the association of more siblings in the home with the early presentation for surgery within 12 months. Perhaps these parents were able to compare the

developmental milestones and the behaviour of the child with cataract with other siblings and identify the problem earlier and access treatment.

The results in this study have shown that children from households in which there were two to three under-five children were more likely to receive medical care late than those from households which had only one under-five. This finding is not surprising in view of the fact that under-five children is a group that mostly requires the attention of primary caretakers within the household. In situations of more than one under-five, when one or all experience an illness it might be difficult to manage all of them at the same time than it is the case when there is only one child in the household. The finding in this study is similar to those reported in other settings. For example, a study conducted in Pakistan found that the number of children in the family was a significant determining factor of the decision to seek healthcare (Nuruddin et al., 2009).

To our knowledge, this is the first multi-centre study aimed at estimating the actual age at presentation for childhood cataract across India. Though the data are obtained from several regions, there are many other service providers in the country who did not participate in this study. But it is important to note that, all the participating hospitals in this study are the main referral centres for treating childhood cataract in their respective locations.

Traumatic Cataract

A very high proportion (24%) of the children who presented for surgery during this study period had traumatic cataract. All these injuries could have been avoided if appropriate health and safety measures for children were in place. For example, a previous report suggests that a safety and awareness programs offered in urban private schools reduced the incidence of eye injuries in children (Gogate et al., 2012). Similar to the previous published reports (Xu et al., 2013), this study also reports higher proportion of traumatic cataract in boys compared to girls and this was due to boys getting involved in more outdoor activities which has access to playing tools that has high potential for harming their eyes (Shah et al., 2012). Also, the children are allowed to play outdoor on their own without adult supervision.

Wooden Stick injuries were found to be more common in this study participants and this results matches with the previous publication from one of the research participant hospitals published a decade ago (Krishnamachary et al., 1997). However, it is very discouraging to

find the proportion of this type of injuries remained the same even after 10 years and this needs more reflection on how to control such injuries in children.

In a previous study from rural India, it was reported that there were only three injuries due to crackers and none due to playing bow and arrow which was a common kind of injury 15 years ago (Gogate et al., 2012). The reduction in these type of injuries was attributed to intense health education through television commercials. However, in the present study four cases were presented with bow and arrow injuries and eleven injuries with fire crackers. This suggests that safety and health education has not percolated to some parts of the region in the country, and that more efforts are required to reduce such injuries in future.

IOL implantation in children with traumatic cataract has found to be effective in achieving better post-operative visual outcome and low rate of serious complications (Eckstein et al., 1998); and in this study around 83% of the children had IOL implantation. However, achieving satisfactory visual outcome following traumatic cataract is very challenging and it's worth investing efforts on preventing such injuries. Focused health awareness programmes targeting wider group of stakeholder's including children, parents, school teachers and health care team to create awareness on how to avoid or minimize such injuries (Adlina et al., 2014). Mass media campaigns such as Television ads on safety measures including avoid touching dangerous materials and increased warnings may be effective in reducing the prevalence of such eye injuries.

4.5.3 Limitations

In general, the sampling in hospital based is biased toward those who have accessed the hospital services. The socio demographic variables among the children who have accessed the services for cataract surgery and those who have not accessed the surgery and remain within the population are always very different. For example, parents who had more knowledge of the condition and its consequences are more likely to have accessed the surgery those without this knowledge. So the generalization of these results to the entire population may not be completely valid. Another limitation of this study was the approach adopted in sample size calculation for this research. As discussed on page 47, the prime aim of this quantitative study was to estimate the proportion of late presentations to childhood cataract surgery and thus the sample size was calculated accordingly.

However, estimating the age at surgery and understanding the reasons for any delay in presentation and /or surgery will provide valuable insights to reduce the time gap between the onset of vision impairing cataract and surgery. The understanding of various socio economic factors that was responsible for the delay from those accessed the services will give insight for developing further studies to understand issues at the community level.

4.5.4 Conclusions

This study confirms that time to surgery for childhood cataract remains a major problem in India. Many socio demographic factors were associated with delay in childhood cataract surgery including parental education, occupation, families reported income and number of siblings living in the family. Also significant variation in the delay between the regions suggests that region specific efforts are required from all stakeholders in the community to ensure the children with cataract receive timely surgical services to reduce blindness and vision impairment caused due to cataract. Addressing these issues will improve the visual outcomes of childhood cataract surgery and thus contribute to achieving one of the main priorities of VISION 2020: The Right to Sight Initiative, (Thylefors, 1998b) reducing blindness and vision impairment in children.

Chapter 5

5 Barriers and enablers to childhood cataract services

Summary

This chapter focuses on the parents'/ carers' perspectives on barriers and enablers to childhood cataract services in India. It starts with an introduction to health seeking behaviour, its determinants and an introduction to implementation science as a basis for systematically assessing the barriers and enablers that can aid in programme development in future, with the aim of reducing the delays in accessing treatment for childhood cataract. The chapter includes an explanation of the Theoretical Domain Framework (TDF) as a means to understand the theoretical basis of the identified barriers and enablers. The results section highlights the various themes generated under the TDF which would help in formulating an implementation plan for bringing positive behavioural changes at the community level.

5.1 Introduction

Health promotion programmes worldwide have long been developed on the basis that providing knowledge about causes of ill health and choices available, will influence individual behaviour to benefit health. However, there is growing recognition, in both developed and developing countries, that providing education and knowledge at the individual level is not sufficient in itself to promote a change in behaviour. Understanding the health seeking behaviour more comprehensively including at the level of the individual, family and the larger community, its influence on the overall process will be beneficial in addressing the gaps in service utilisation (Rimal, 2000).

Health care seeking behaviour (HCSB) has been defined as 'any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy' (Olenja, 2003). HCSB is preceded by a decision-making process that is further governed by individuals and/or household behaviour, community norms, and expectations as well as provider-related characteristics including availability of various health care facilities, their accessibility and behaviour of the health care team (Oberoi et al., 2016).

In this context, HCSB means, early recognition of symptoms, timely presentation to health facilities and compliance with effective treatment. All these factors to some extent to reduce the visual impairment and blindness caused due to cataract in children. In particular, health-seeking behaviour can be described with data such as the time difference between the onset of an illness and getting in contact with a healthcare professional, type of healthcare provider patients sought help from, how compliant patient is with the recommended treatment, reasons for choice of healthcare professional and reasons for not seeking help from healthcare professionals.

In the absence of universal health coverage through the health system, the decision making for healthcare at the household level takes into account various factors including public or private care, modern or traditional services (Tipping, 2000), or indeed decision not to take up available health services at all. The ultimate end point of the decision making process is the utilisation of available health care services which can have a profound effect on the population's health.

Detailed analysis of health seeking behaviour including health care utilisation has therefore increasingly been a major focus for researchers and policy makers. Both quantitative and qualitative methodologies should be used to understand the multi-faceted issues such as affordability, social support and decision making, which will aid in a better understanding of health seeking behaviour (Ward et al., 1997).

5.1.1 Determinants of Health seeking behaviour

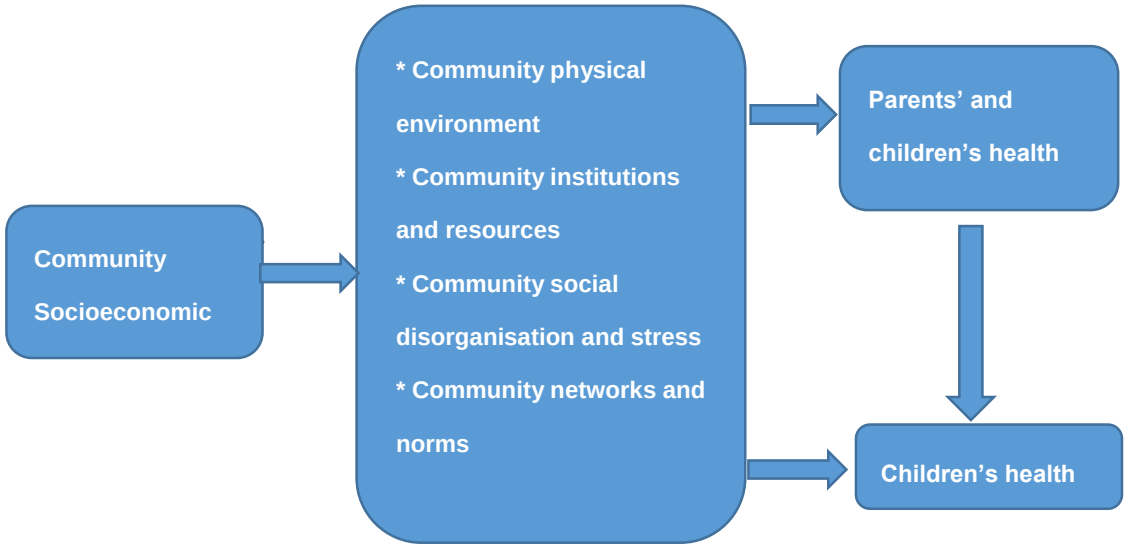
Empirical evidence suggests that health-seeking behaviour is influenced by numerous factors. The review of literature from developing countries suggests that factors such as educational level, maternal occupation, marital status, economic status, age and sex, health care costs, women's status, type and severity of illness, distance and physical access, and perceived quality of service provision play a role in determining individuals' actions in relation to their health (Tipping and Segall, 1995).

Further, the patients' previous experience with healthcare facilities contributes most to observed delays in accessing the health care facilities (Kassile et al., 2014). Previous research from a low income country (Adinan et al., 2017) found that children coming from communities with levels of education above national averages have higher odds of being

taken to appropriate health care facilities, compared to those from the communities with lower education.

Community socioeconomic context is considered as one of the fundamental determinants of population health. Previous research (Lei, 2017) has established a strong association between neighbourhood disadvantage and its adverse impact on a wide range of health-related outcomes, including health behaviours. The HCSB of the parents and the community they live in including the availability of physical infrastructure and the norms been practised within the communities has a profound effect on children's health. Figure 5.1 highlights the theoretical mechanisms for the effect of community Socio economic status (SES) on children's health (Lei, 2017)

Figure 5.1 Theoretical mechanisms for the effect of community SES on children's health



Source: Lei, 2017

5.1.2 Implementation Science

Implementation science is the study of methods to promote the integration of research findings and evidence into policy and practice. It seeks to understand the behaviour of healthcare professionals and other stakeholders as a key variable in the sustainable uptake, adoption, and implementation of evidence-based interventions. As a newly emerging field, the definition of implementation science and the type of research it encompasses may vary according to the research context. However, the intent of implementation science and related research is to investigate and address major bottlenecks (e.g. social, behavioural, economic, management) that impede effective implementation, test new approaches to improve health programming, as well as determine a causal relationship between the intervention and its impact (Eccles and Mittman, 2006).

Interventions are used to promote uptake and optimal use of effective clinical services, and to promote healthy lifestyles. However, barriers to implementation may arise at multiple levels of healthcare delivery: the patient level, the provider team or group level, the organizational level, or the market/policy level (Ferlie and Shortell, 2001). Addressing these barriers requires changes at various levels including health care structure, policy and behaviour change which is quite challenging at all levels (Abraham et al., 2009).

Many factors are responsible for influencing the uptake of available services and the success of the implementation depends on detailed assessment of barriers and enablers of the behaviour to be changed. In healthcare research, there are many theoretical models that explain behaviour (Michie et al., 2014) however, these are often difficult to access and understand by health professionals who do not have a psychology background (Michie et al., 2005a).

An integrative framework, the Theoretical Domains Framework (TDF) was designed for systematically identifying and assessing barriers and integrates 33 theories of behaviour change (Mosavianpour et al., 2016). The original TDF was developed in 2005 with 12 domains and 128 constructs and in 2012, the framework's validity was re-evaluated and a refined version of the TDF with 14 domains and 84 constructs was proposed (Cane et al., 2012). However TDF is the single tool that has been designed specifically to assess all kind of barriers and enablers systematically. In this research the earlier version with 12 TDF domains are used and it includes 1) knowledge, 2) skills, 3) social/professional role and

identity, 4) beliefs about capabilities, 5) beliefs about consequences, 6), Motivation and goals, 7) Memory, attention and decision processes, 8) environment context and resources, 9) social influences, 10) emotion, 11) nature of the behaviour and 12) behavioural regulation (Michie et al., 2005b).

This approach has been predominantly focused on implementation challenges within the health care system mainly used to assess the behavioural pattern of health professionals, and in the recent past the TDF has been used increasingly to understand the patient level uptake of health behaviours (Burgess et al., 2015, Gray-Burrows et al., 2016, Dyson et al., 2010). To date, the published literature suggests this framework has been used to analyse the barriers and enablers three times in the field of eye care. One study looked at the factors influencing the uptake of retinal screening among patients with Type 2 diabetes (Lake et al., 2017). A second study was a systematic review protocol to identify barriers and enablers to diabetic retinopathy screening attendance (Graham-Rowe et al., 2016) and a third study focused on the professionals' perspectives to address depression in a vision rehabilitation setting (Holloway et al., 2016).

The main aim of this study was to develop an implementation plan aimed at increasing the uptake of childhood cataract services.

The objectives of this study were:

- Identify barriers and enablers associated with the access to childhood cataract services
- Map out the theoretical domains underpinning the identified barriers and enablers applying TDF approach
- Interpret and identify all the key domains and themes for developing an implementation plan
- Design a detailed questionnaire based on this research findings covering all TDF domains to assess the barriers and enablers to access eye care services from the receivers' perspectives

5.2 Methods

Study Design

A sequential explanatory design was used to collect data for this study. The description of this design is explained in detail in Chapter 2: Methods. In brief, this design involved quantitative data collection followed by a qualitative analysis for a deeper understanding of the complex social, family, community, financial and gender issues relating to barriers to uptake of childhood cataract surgery. The quantitative data were collected using a questionnaire (See Chapter 2: Methods section on how this questionnaire was developed) and included information on barriers to access to eye care services, by using an 11-item list with an additional option to express any barriers that were not covered by the list. For each of the selected barriers, responses were recorded on a five point Likert scale ranging from “low importance to high importance”. This 11 item list comprised of various issues faced by the parents/ carers to access the cataract surgical services after the cataract in child was recognised and advised to seek health care intervention. A copy of the questionnaire is attached as Appendix 3. The items included the following:

1. Child too young for surgery
2. Problem is not very severe
3. Distance
4. Economic reasons
5. Didn’t know where to go
6. Child had other health problems
7. Fear of surgery
8. No one to look after others in the family
9. Language problems
10. Delay in getting hospital appointment
11. Other reasons, specify

5.2.1 Study participants selection

The quantitative data were collected using a questionnaire at the hospital when the parents admitted their child for cataract surgery. The methodology was discussed in detail in Chapter 4. Briefly, the questionnaire was administered by a trained hospital staff member in the local language to all the parents who admitted their child for cataract surgery during the study period and who had consented to participate in the study.

The samples for the in-depth interviews were selected using a stratified purposive sampling method to capture diversity from parents with varied experiences. The stratification was done according to the child's surgery status including:

- children who had their cataract surgery without any delay, (delay is defined as surgery completed later than three months from recognition of the condition)
- children who had delayed surgery,
- Children who have been advised for surgery but not completed their cataract surgery,
- Children who sought cataract treatment at the free section and those who sought cataract treatment at the paying section.

It was planned to conduct three to four Interviews per hospital location and continue until data saturation was achieved (Francis et al., 2010).

The in-depth interviews were conducted at each of the 9 participating hospitals with the parents who presented for cataract surgery for their child. All parents who attended the hospital on the days when the investigator was present were invited to participate in these interviews. These included parents in paying and non-paying categories. Some of the parents had coincidentally also participated in the quantitative study.

During the in-depth interviews at the hospital, it was realised that it would be an added advantage to capture the perceptions of parents and caregivers who have been advised that their child should be taken to the hospital for cataract surgery but have not done so. For these home interviews, two hospitals were selected on a random basis from lists of children advised to have cataract surgery and did not undertake the surgery. For practical reasons, the families residing within 15 kms of the hospital were selected from the list and telephone enquiries were made to check their availability and their consent to participate in the interview. Based on the verbal consent the home visits were made and written consent was obtained before the actual interview.

5.2.2 Interview Setting

The in-depth interviews were conducted at the hospital or at the participants' home as appropriate. Entire interviews were audio taped with prior consenting for transcription. Interviews were conducted in a separate room at the hospital to ensure privacy and to avoid any disturbances. Home interviews were conducted with pre-arranged appointments with the

family according to their convenience. The principal researcher (SS) and a support staff member from the hospital visited the participants' home and conducted the interview. Either parent or both parents and on a few occasions other relatives participated in the discussion. In some locations language interpreters were selected from local research partner hospitals who had prior experience in interacting with local communities on various issues and had the language skills to interpret in both Hindi and other regional languages. Time duration for interviews ranged from 40 to 90 minutes. Each interview started with an introduction by the researcher and the interpreter reassure the parents that the interview was confidential and would not affect the treatment for their child for now or in future.

5.2.3 Topic guide

All the interviews were guided by a pre designed topic guide as shown below. The topic guide was developed with the intention of helping the researcher to stay focused on the topic and ensure all important question were raised during the interview. However, the structure allowed the researcher sufficient flexibility to permit topics to be covered in an order most suited to the participants, to allow responses to be fully probed and explored and allow the researcher to be responsive to issues raised spontaneously by the participants (Ritchie et al., 2013).

Topic guide for in-depth interviews with parents

Introduction

- Thank participants for agreeing to take part
- Do you have any questions regarding our information sheet?
- Explain that this session will be aimed at getting their views about the issues involved in accessing cataract services for children
- Explain that the session is about their views in general along with their personal experiences with their child
- Session will last approximately 1.5 hours

Respondent introductions

- Please tell me a bit about yourself / your family/ age range of the respondent and spouse/ education and occupation of both parents/ how many children you have and their ages/

Knowledge about childhood cataract

1. What is cataract?
2. How might cataract affect a child's vision and/or their life?
3. Is cataract in children preventable or treatable? If so how?
4. What are some of the main reasons on why some children develop cataract?
5. Are there any self-practices adopted for treating cataract in your communities?

Attitude to accessing childhood cataract services

1. When do you think the child with cataract should be taken to an eye specialist?
2. At what age can a child undergo surgery for cataract? Would it be ok to delay surgery until your child is grown up?
3. What is the decision making process in your household for accessing eye health services?
4. What are the risks and benefits for a child to undergo cataract surgery?
5. Is cataract surgery the end of the treatment? If yes, why do you think so? If not what else is required
6. Is there any gender disparity in accessing the services?

Probe on:

- Follow up period / care required
- Issues in attending follow up care

7. Are there any problems in accessing cataract services for children? Explain at the family, community and at the hospital level

Probe on:

- Access related
- Affordability
- Dependability / dependants
- Fear
- Cultural reasons etc.
- Problems at the Hospital
- Any special foods good for eye health

8. How to ensure the children with cataract completes their treatment on time?

Probe on:

- Whose responsibility is this?
- What is needed?
- The child his / her condition
- Can you please explain about your child's eye problem?
- Probe on
- Child's age
- What was the problem?
- When it was noticed? By whom?
- Did anyone else in the family has similar problem?
- What did you do on recognition of the problem?
- Surgery status – when was surgery completed? Prognosis: what will happen in the future – will the condition develop, improve, and deteriorate?
- If surgery not completed – why?
- Finally, is there anything you would like to add about this topic before concluding the interview?

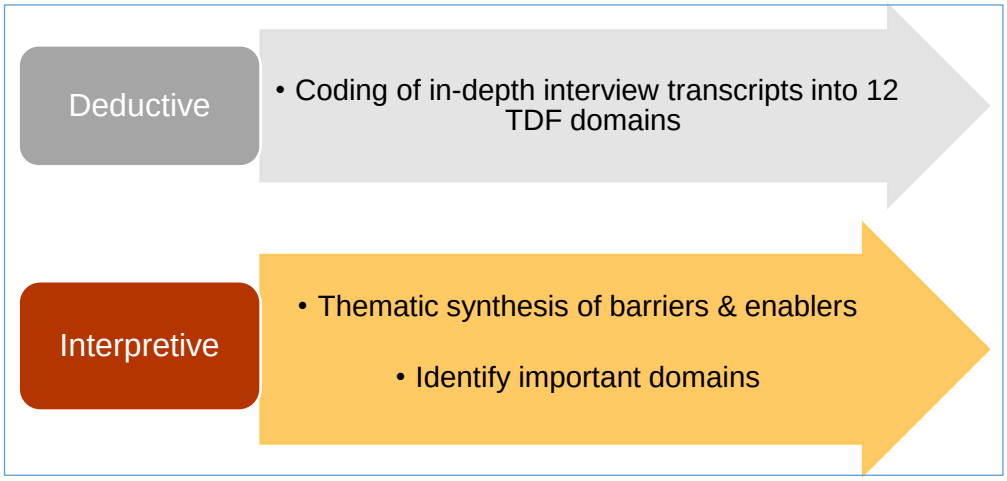
  END

5.2.4 Data coding and analysis

Quantitative data were managed using an Excel data sheet and analysed using SPSS version 22. A verbatim transcript of each interview was prepared from the tape recording of the sessions and imported into NVivo 11 for data management and analysis (QSR-International., 2013). Transcription of all audio tapes was done externally by an independent company, and the researcher reviewed the transcripts for accuracy and completeness. To maintain anonymity, names of the participants were removed from transcripts. The researcher (SS) read all the 35 interview transcripts multiple times before coding the transcripts using the Theoretical Domain Framework (TDF).

Figure 5.2 shows the steps involved in thematic analysis. Every extracted statement was coded based on the 12 domains of TDF (Michie et al., 2005b), either into one domain or into multiple domains. If the statement fitted more than one domain for example, an extracted quote from a father saying, "*We felt very sad. She is so young and she has got cataract! What would happen if we get her married? Problems can arise. So, without delay surgery should be done"* would be coded to both "Beliefs about consequences" and "Social Influences" domains.

Figure 5.2 Steps involved in thematic analysis



Both deductive and interpretive approaches were used to ensure all themes were coded. As part of interpretive analysis, the focus was given to sifting and sorting the data to thematically synthesise and to identify key domains and key emerging issues under each identified domain. Two factors were used to identify the "importance criteria" (Graham-Rowe et al., 2016), key domains which are likely to be the most important for influencing the access to childhood cataract services.

1. The number of beliefs identified as barriers and enablers under each domain and,
2. The expressed importance within each domain. This was primarily a qualitative judgement made by the researcher by considering the meaning, interpretation and prioritisation of the data as the research had closer familiarity with the primary data obtained in the study as she was present during each in-depth interview conducted in this research.

To check the validity of the coding, a sample of 20% of all interview transcripts were randomly picked and coded independently by another researcher (CS). The agreement between the two researchers was assessed in a meeting by reviewing all the codes assigned to each of the 12 TDF domains. The inter coder reliability between the researchers had high agreement over 90% on all domains except on the domain on 'Memory, attention and decision processes'. This domain was focused on the individual's ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives which is focused primarily on the cognitive ability of the individuals. It was

discussed and agreed between the researchers to include codes related to decision making into the domain ‘social influences’ and not under ‘Memory, attention and decision processes’. Similarly, all disagreements or uncertainty were discussed and a final theme was chosen.

5.3 Results

5.3.1 Quantitative Results

Of the 751 subjects, 179 children presenting with traumatic cataract were excluded. A total of 572 parents / carers who presented for cataract surgery for their child were interviewed at the hospital. Of the 572 parents / carers, 245 (57%) of them reported accessing an eye hospital more than three months following identification of the child’s eye condition. Another 114 (20%) reported delay (later than the advised period for surgery at the hospital; the time period varied for each individual child) in undergoing surgery after it was advised. All those who had delayed access to hospital and surgery by more than 3 months completed the barriers section on the questionnaire and Table 5.1 shows the socio demographic details of these participants.

Table 5.1 Socio demographic details of the participants who reported delay in accessing hospitals and for the surgery

Variables	Delayed access to hospital (> 3 months after identification) (n = 245)	Delayed surgery after advised (later than recommended period for surgery at the hospital) (n = 114)
Gender		
Male	138 (56.3)	69 (60.5)
Female	107 (43.7)	45 (39.5)
Age of the child		
Under 1 year	31 (12.6)	20 (17.5)
1 – 3 years	22 (9.0)	17 (14.9)
3 – 10 years	97 (39.6)	44 (38.6)
>10 years	95 (38.8)	33 (28.9)
Cataract Type		
Congenital	122 (49.8)	67 (58.8)
Developmental	123 (50.2)	47 (41.2)
Location		
Rural	225 (91.8)	92 (80.7)
Urban	20 (245)	22 (19.3)
Region		
South & West	80 (33.1)	47 (41.2)
North & East	164 (66.9)	67 (58.8)
Mothers' Age		
<30 years	133 (54.3)	61 (53.5)
30 and above	112 (45.7)	53 (46.5)
Fathers' Age		
<30 years	73 (29.8)	38 (33.3)
30 and above	172 (70.2)	76 (66.7)

Table 5.1 The socio demographic details of the participants who reported delay in accessing hospitals and for the surgery

Variables	Delayed access to hospital (> 3 months after identification) (n = 245)	Delayed surgery after advised (later than recommended period for surgery at the hospital) (n = 114)
Mothers' occupation		
Not working	174 (71.0)	93 (81.6)
Working	71 (29.0)	21 (18.4)
Fathers' occupation		
Daily Labourers	198 (80.8)	69 (60.5)
All others	47 (19.2)	45 (39.5)
Mothers' education		
No education	107 (43.7)	41 (36.0)
Any education	138 (56.3)	73 (64.0)
Fathers' education		
No education	95 (38.8)	29 (25.4)
Any education	150 (61.2)	85 (74.6)
Family Income per month		
<INR 5000	125 (51.0)	43 (37.7)
>INR 5001	120 (49.0)	71 (62.3)

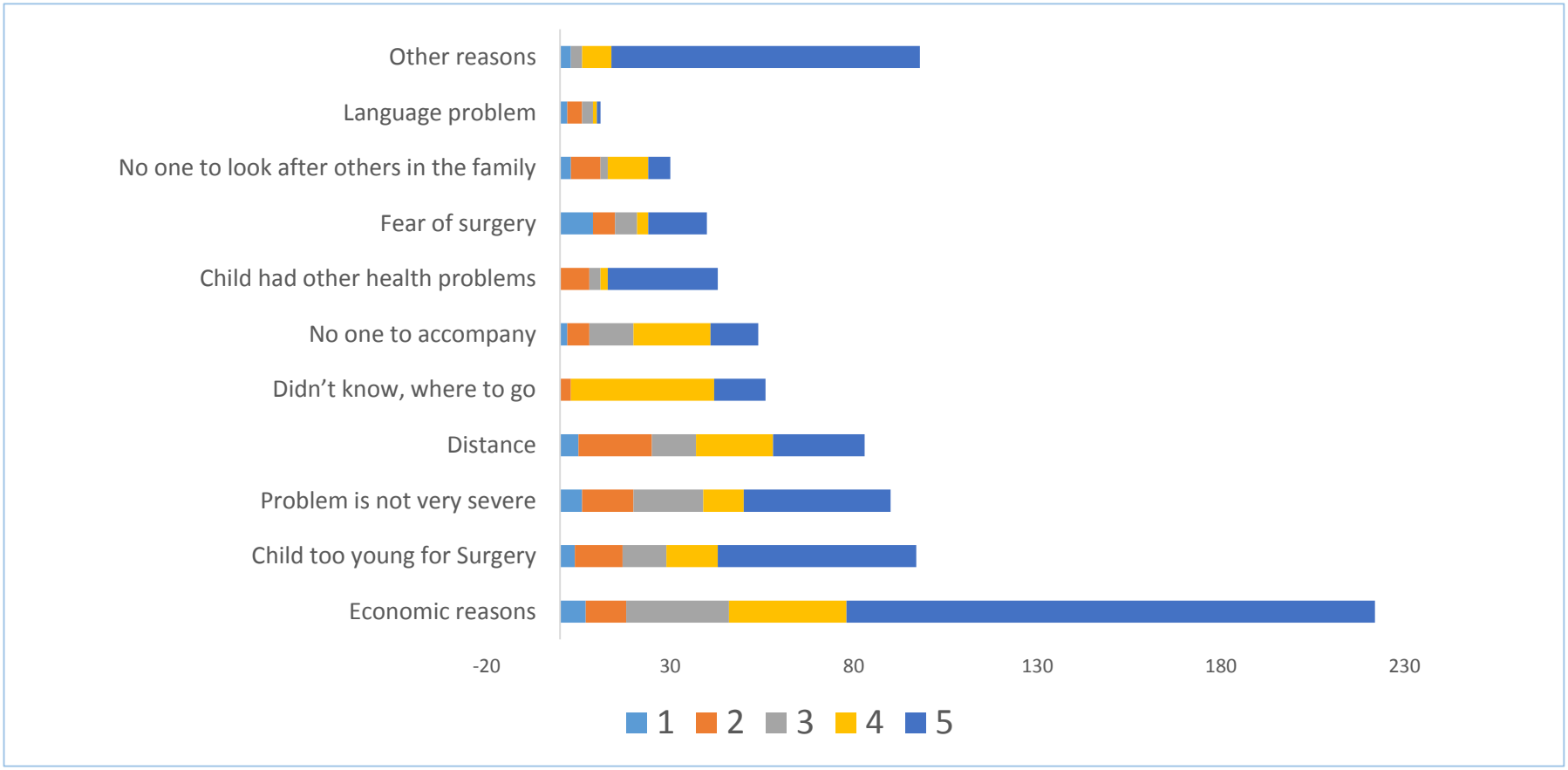
A total of 831 barriers were reported including 603 relating to a delay in accessing the hospital and 228 relating to the delay in undergoing the surgery after it was advised by the hospital. A mean number of barriers of 2.5 per participant were recorded for access delay. The five most commonly reported barriers were: economic reasons (40%; n=222), child considered too young for surgery (17%; n=97), the problem was not considered as severe (16%; n=90) long distance to the facility (14.5%; n= 83) and a lack of knowledge by the parents /carers of which hospital to attend (10%; n=56). The details of self-reported barriers are presented in Table 5.2.

Table 5.2 Self-reported barriers to accessing the hospital services for childhood cataract

Self-reported Barriers	No of responses		
	Access delay	Surgery delay	Total
Economic reasons	177	45	222
Child too young for surgery	83	14	97
Problem is not very severe	77	13	90
Distance	55	28	83
Didn't know, where to go	52	4	56
No one to accompany	37	17	54
Child had other health problems	16	27	43
Fear of surgery	30	10	40
No one to look after others in the family	23	6	29
Language problem	10	1	11
Other reasons	43	63	106
Total	603	228	831

For each of the reported barriers, the participants were asked to rate its importance on a 5-point scale, with 1 as least important and 5 as most important barrier to delay. More than one barrier was reported by each participant and the rating is shown in Figure 5.3. A total of 831 responses were recorded of which 427 responses were given a rating of 5. Among these 5-rated barriers, economic reasons were cited by 144 (33.7%) of individuals, child considered too young for surgery were cited by 45 (10.5%) individuals and problem considered not severe by 40 (9.4%) individuals. Among the other reasons for delayed surgery, in 16 children a local ophthalmologist advised the parents to delay the surgery and in 33 cases, the child had medical fitness issues.

Figure 5.3 Rating of reported barriers using 5 point scale

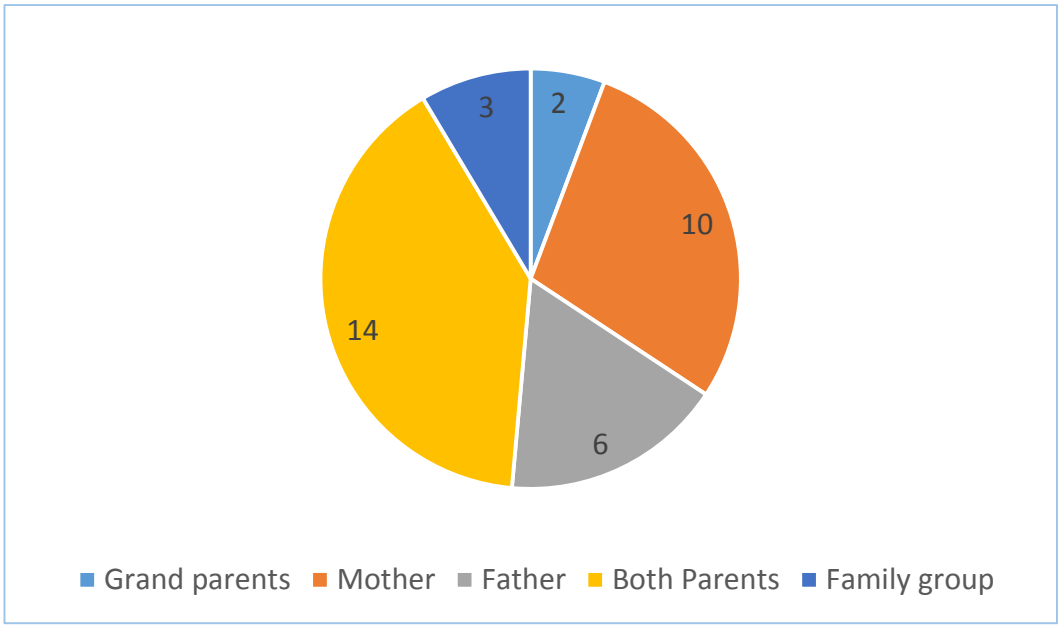


(1 indicating low importance to 5 as high importance)

5.3.2 Qualitative results

A total of 35 in-depth interviews were conducted with a randomly selected sample of parents/ carers. Of the 35 interviews 30 were conducted in the hospital premises and 5 in the participants' home. The number of in-depth interviews and the interviewee's relationship to the child is shown in Figure 5.4. The 'family group' includes parents, siblings and grandparents in most cases, a few other relatives were also participated in the discussion.

Figure 5.4 Number of in-depth interview participants' and their relationship to the child



Based on the interview transcripts, a total of 632 quotes were coded covering 11 out of 12 TDF domains. No quotes were consistent with the domain of ‘memory, attention and decision processes’. A summary on the number of quotes coded under each TDF domain is presented in Table 5.3. Quotes representing positive factors that enabled the parents/ carers to access the services early were coded as enablers and the quotes that were judged to contribute to surgical delay were coded as barriers and Table 5.4 shows the TDF domains associated with the access to cataract services.

Table 5.3 Summary of the number of quotes coded under each TDF domain

TDF Domains	Barriers (n)	Enablers (n)	Total (n)
Beliefs about consequences	74	67	141
Social influences	48	68	116
Environmental context and resources	77	17	94
Motivation and goals	27	59	86
Knowledge	24	40	64
Emotions	35	21	56
Beliefs about capabilities	11	22	33
Behaviour regulation	3	16	19
Nature of behaviour	10	6	16
Skills	4	3	7
Social professional role and identity	2	9	11
Memory, attention and decision processes	0	0	0
Total	317	328	643

Once the transcripts were coded into TDF domains, they were further screened and grouped under major themes. A summary of the number of themes identified under each TDF domain is presented in Table 5.4.

Table 5.4 Summary of the number of themes/ constructs identified under each TDF domain

TDF Domains	Barriers (n)	Enablers (n)	Both Barriers and Enablers (n)
Beliefs about consequences	3	3	7
Social influences	6	1	2
Environmental context and resources	4	0	4
Motivation and goals	2	3	3
Knowledge	0	4	2
Emotions	3	0	3
Beliefs about capabilities	1	0	2
Behaviour regulation	3	3	0
Nature of behaviour	1	0	3
Skills	0	2	1
Social professional role and identity	0	1	1
Memory, attention and decision processes	0	0	0
Total	23	17	28

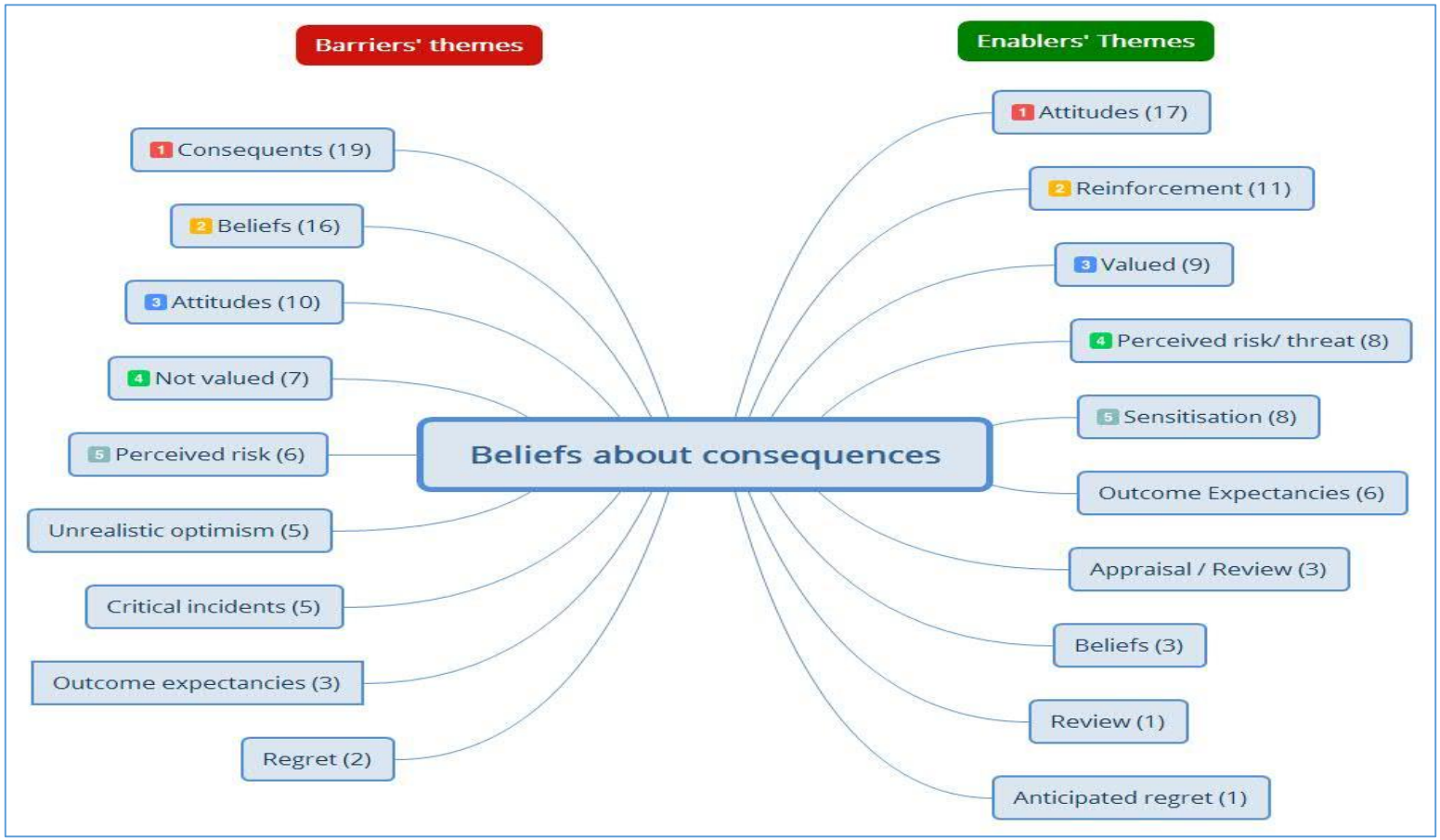
A total of 68 themes were identified, including 23 related to barriers, 17 related to enablers and 28 themes represented both barriers and enablers. The description of results of each TDF domain is presented here. A few sample excerpts identifying both enablers and barriers are included in Table 5.5 and Table 5.6 respectively. The complete results from in-depth interview sorted by TDF domain on Enablers and Barriers are included as Annexure 9.6.1 and 9.6.2 respectively.

1. Beliefs about consequences

Participants' 'beliefs about consequences' regarding accessing or not accessing cataract surgery were identified as an important domain responsible for both barriers and enablers. A total of 19 themes were identified under this domain including 9 themes under barriers and 10

themes representing enablers for accessing services and Figure 5.5 shows the themes title and the order of importance as identified.

Figure 5.5 Barriers and enablers themes identified under the TDF domain 'Beliefs about consequences'



The number within brackets indicates the number of quotes identified under each theme.

1.1 ENABLERS

In general, the participants expressed many positive 'consequences' that enabled them to access the services. Attitude towards treatment, reinforcement by doctors, priority given to the issue and perceived risk / threat were the major themes identified under the enablers for this domain. Some of the participants' quotes are listed below for each of the identified theme in italics. Table 5.5 shows a few sample interview excerpts reflective of the theme 'Beliefs and consequences' as an enabler.

1.1.1 Attitudes towards treatment

If the parent realised the importance of eye treatment for their child they would be more likely to take their child for treatment.

…We felt… but, then we thought it is about the eyes and eyes are everything. So surgery is necessary. My elder brother also came with me. So, we quickly took the decision to go ahead with the surgery and admitted her. (Parents, Id 10)

1.1.2 Reinforcement by doctors

The doctors at the hospital played a pivotal role in enabling timely treatment, since they were in a position to reinforce the necessity of early treatment directly to the parents.

The doctors told us that the surgery should be done immediately as with time the situation of the child would worsen. They showed me children aged as little as 4 months on whom surgery had been done and tried to convince me. They said that it is quite normal. After knowing all this, I became confident and went ahead with the surgery. (Father, Id 4)

1.1.3 Priority

When the parent sees a benefit of treatment in their child, they are likely to give higher priority to spending time and money to make treatment possible.

Doctor said that spectacle will be required. So, I am getting it done here. There is no difficulty... Now that my child is able to see after surgery. I will feel good to come back, hoping that he would see better… (Father, Id 13)

1.1.4 Perceived risk / threat

The parent may perceive the surgical treatment or lack of treatment as a risk or threat. For example, they may perceive that the presence of cataract will affect their child's future life, or they may perceive a risk of eye surgery, making it more or less likely that they will take the child for treatment.

We felt very sad. She is so young and she has got cataract! What would happen if we get her married? Problems can arise. So, without delay surgery should be done… the problem might increase. It is possible that it might not be cured by surgery even. (Father, Id 16)

1.1.5 Sensitisation

This refers to the parent being sensitised to the signs and symptoms of childhood cataract. If the parents had adequate knowledge about signs and symptoms of a child with visual difficulties related to cataract, this would enable earlier cataract services uptake.

Parents should notice if the children have any difficulty in reading. If the child is keeping the book too close while reading. If the child is having any problem in reading they should immediately take the child to the hospital. (Mother, Id 23)

1.2 BARRIERS

Though there are many enablers reported by the participants, the concept of 'beliefs about consequences' also caused significant barriers that contributed to delay in accessing cataract services. Most important themes under the barriers category included, consequences, beliefs, attitudes and not a priority. Traditional / cultural beliefs based on spirituality and old practices were also found to be a major impediment for accessing cataract services for the children. Some of the participants' quotes are listed below for each of the identified themes in italics. Table 5.6 shows a few sample interview excerpts reflective of the theme 'Beliefs and consequences' as a Barrier.

1.2.1 Consequences

This refers to the parents' perceived consequences of delayed cataract surgery for their child. Though some parents understand the consequences of delayed treatment, they may still delay accessing treatment due to a perception of other consequences, and these are also reflected in this category.

It took 2-3 months for us to bring her for the surgery. Mainly, I took time to make up my mind. I was very emotional. We thought about her career ….. Better if it is done in the right age. It is very important for a child. Especially a girl child. (Parents, ID 22)

1.2.2 Beliefs

Parents' responses suggested that beliefs in traditional healing impeded access to cataract services for their children.

Baba (local traditional healer) gave him some medicine and suggested to put it on the eye lashes… so that the cataract will get cured. We did for 2-3 months and it didn't work. (Father, Ref Id 13)

1.2.3 Attitudes

A negative attitude towards preventive care such as regular eye screening for early detection contributed to a delay in accessing cataract services in children.

No…. we never thought the child should go for an eye check-up when there is no problem... Only if there is a problem, children should be taken for check-up. Otherwise not necessary. (Parents, Ref ID 10)

1.2.4 Not a priority

When the child complains about any eye problem, or if an eye problem is perceived by others such as parents or teachers, the parents in some cases did not consider this to be a priority compared with other commitments and responsibilities.

She had it even before but our family did not notice it …She was in year 8. She used to live in the hostel. She informed us that she can't see properly... But we laughed it off … she was so young. How could she see less? Nobody understood. Not even me. When it increased, she told us again after 2 months... Then we showed her to the doctor there. (Father, ref Id 16)

1.2.5 Unrealistic optimism

Various traditional practices are common in rural areas and the spiritual belief is quite common among both urban and rural populations.

It happened since he was born. Now he is 4 years old. It is there since four years. We kept on thinking that it will go away, it will be cured. We kept on going to "babaji's place" [local priest]. People recommend this place to visit… to get cured. That's it … and the time kept passing on… (Father, Ref Id 13).

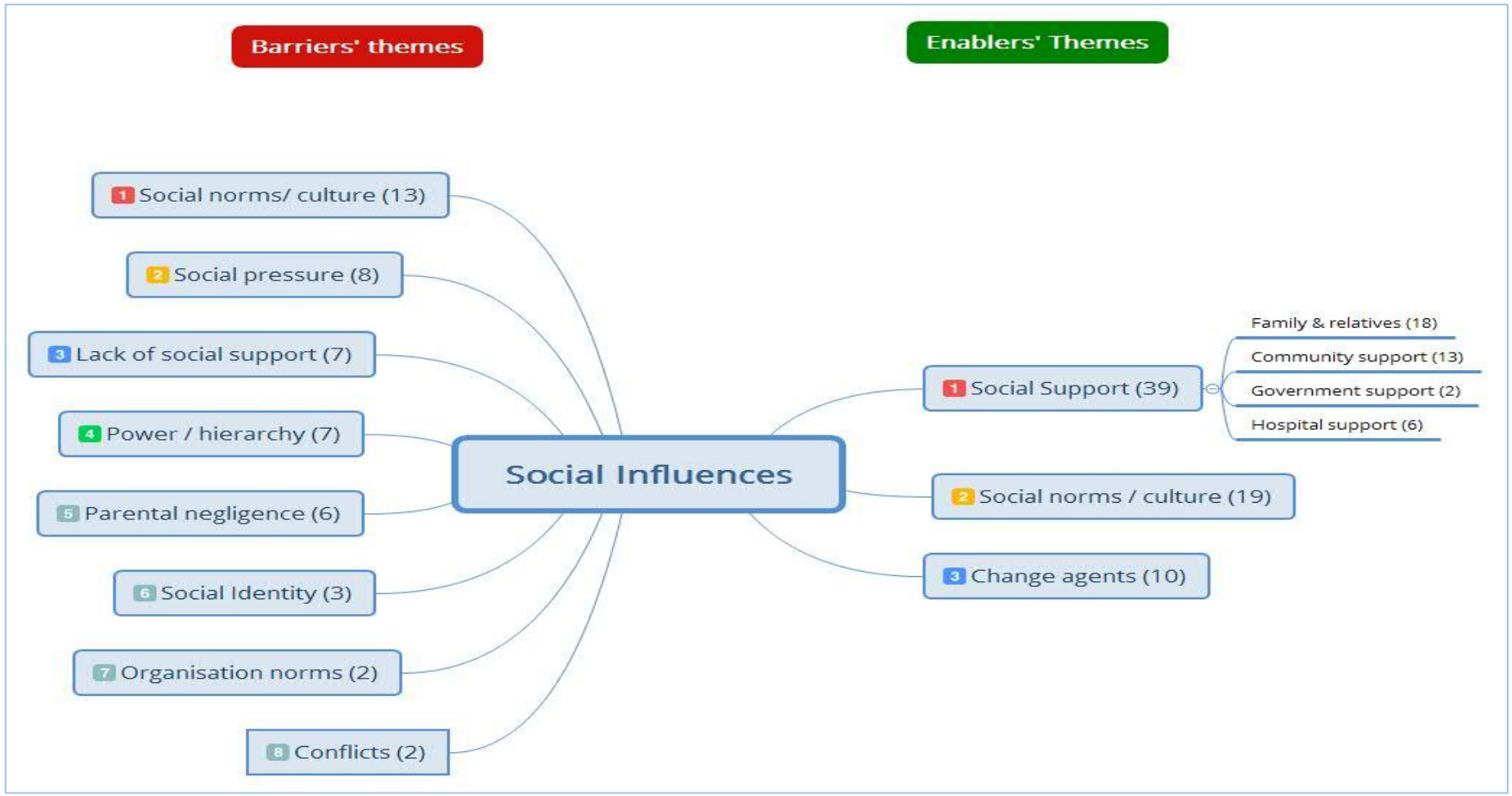
2. Social Influences

The second most important TDF domain identified was "Social Influences".

The social structure of the family and the extended community had a significant impact, both positively and negatively, on the decision making processes to accessing cataract services. These included an individuals' support in identifying or recognising the problem, help in arriving at an appropriate decision and most importantly the support extended either in accompanying the parent/carer to the hospital or looking after the young siblings when the parents are away receiving hospital care. Those interpersonal processes that can cause individuals to change their views, feelings, or behaviours are grouped under this domain.

A total of 11 themes were identified under this domain including 8 themes under barriers and 3 themes representing enablers for accessing services and Figure 5.6 shows the themes and their order of importance.

Figure 5.6 Barriers and Enablers themes identified under the TDF domain Social Influences.



The number within brackets indicates the number of quotes identified under each theme.

2.1 ENABLERS

The major themes identified as enablers under the TDF "Social Influences" are 'Social support', 'Social norms/ culture' and change agents at the community. Some of the participants' quotes are listed below for each of the identified themes in italics. Table 5.5 shows a few sample interview excerpts reflective of each theme as an enabler.

2.1.1 Social support

Social support includes support from family members and relatives, the wider community, government and from the hospital. Support from all the stake holders were identified as enabler for accessing the services.

In the rural areas people don't have money. So, major decisions are taken after the family members sit together and decide on where the money will be arranged from and how. Sometimes neighbours and / or relatives are also involved. (Parents, ref Id 3)

2.1.2 Social norms/ culture

Many participants reported that changes on social norms has been found when it comes to decision making for their children. Some women are making the decision to take their child to the hospital when required even in rural communities and this has been accepted by the male members of the family. For example:

I take the decision as a mother and my husband doesn't say anything. Even in the neighbourhood as well men do not have time … they are busy with their work. Children's issues need to be looked after by their mothers. (Mother, ref Id 23)

2.1.3 Change agents

There were a few champions identified at the community level who are currently guiding the parents/ carers to seek appropriate care. They included the ASHA workers (Accredited Social Health Activist) appointed by the government to improve the health of rural communities. Significantly, parents whose children have already received care at the hospital were identified as champions of change within their communities.

You (The hospital) are here. But we come to you. So your publicity will happen through us. We go back and tell people that the doctors at this hospital are good, it has the best facilities. (Father, ref Id 16).

2.2 BARRIERS

Social Influences also significantly contributed to the delay in accessing the services. The major themes identified as barriers under this domain were ‘Social norms/ culture’, ‘Social Pressure’, Social support and the ‘power and hierarchy’ at the family level. Some of the participants’ quotes are listed below for each of the identified theme italics. Table 5.6 shows the interview excerpts reflective of the theme ‘Social Influences’ as Barrier.

2.2.1 Social norms/ culture

Cultural and societal norms within the society dictate to some extent the relatively low priority given to vision and eye care for children.

We felt very sad. She is so young and she has got cataract! What would happen if we get her married? Problems can arise in her marriage life. (Father, ref ID 16)

2.2.2 Social Pressure

Social and peer pressure for the parents to try alternative forms of treatment resulted in delay in accessing cataract surgical services in children.

Yeah, people said about Ayurveda treatment. We had tried with Ayurveda in parallel and came to know that by applying Ayurveda medicines in the eyes cataract could be cleared. When we came for the surgery we received calls suggesting us to not to go for the surgery… (Parents, ref ID 18).

2.2.3 Social support

Pressure and a lack of empathy from peers acted as an emotional barrier among the children with cataract and their families.

I can't see the board clearly. I try to read the words one by one. Many in my class tease me calling me 'blind'. (Child with cataract, ref ID 30)

2.2.4 Power and hierarchy

Parents in law played a major role in overall decision making for health care visits in several rural families. Unless they are convinced about the treatment they will not allow their

grandchildren go for surgery even the mother is willing to do. For example, a mother in rural area expressed it as:

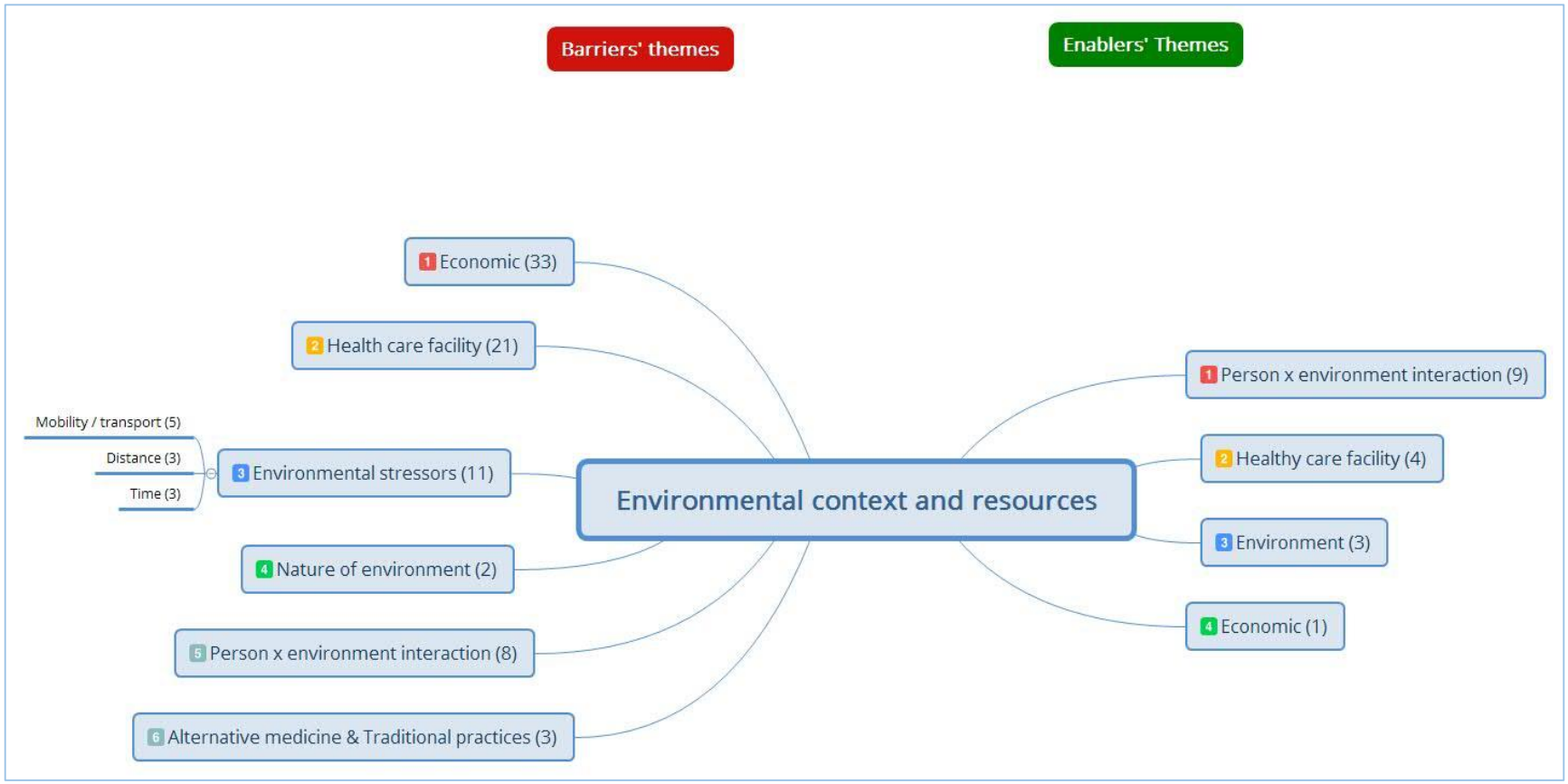
I have accumulated the money for his operation … But my in laws were not allowing us to go for surgery as everyone feels the child is too young... (Mother, ref ID 26)

3. Environmental context and resources

This TDF domain was found to be a major contributor to barriers. This domain covers the majority of factors identified in the questionnaire as important barriers such as availability, accessibility and affordability.

A total of 12 themes were identified under this domain including 8 themes under Barriers and 4 themes representing enablers for accessing services and Figure 5.7 shows the theme titles and their order of importance.

Figure 5.7 Barriers and Enablers themes identified under the TDF domain 'Environmental context and resources'.



The number within brackets indicates the number of quotes identified under each theme.

3.1 ENABLERS

The major themes identified as enablers under the TDF "Environment context and resources" are 'Person X environment interaction' and 'Health care facility'. Some of the participants' quotes are listed below for each of the identified themes italics. Table 5.5 shows a few sample interview excerpts reflective of the theme 'Environment context and resources' as an enabler.

3.1.1 Person X environment interactions

The environment in which the individual lives and the interaction with their community was found to play an important role in health seeking behaviour.

People have become more aware nowadays. There are so many programs running in the villages, the ASHA worker is there, she keeps on meeting and talking to people. (Parents, ref Id 10)

3.1.2 Health care facility

Access to the nearest health care facility, availability of free services and awareness about the services available were found to be enablers.

We live near a sugar factory where there is a government hospital. We been there and checked the eyes and they advised cataract surgery. Since we were aware about this hospital we came directly to this hospital, as there was no need to ask any one. (Grandparents, ref Id 1)

3.2 BARRIERS

Compared to enablers, this domain was predominantly associated with barriers, the most important barriers identified were 'Economic reasons', followed by 'Health care facility' and 'Environmental stressors'. Table 5.6 shows the interview excerpts reflective of the theme 'Environmental context and resources' as Barrier.

3.2.1 Economic reasons

The cost involved in seeking services was found to be the major barrier in this research. Although the surgical services are available at no cost at the participating hospitals, the cost

involved to access the free surgery and the opportunistic cost, mainly lost wages due to hospital attendance, may be significant.

I do labour job… It is labour job. If you go, you get (wages), if you don't go, you don't get...and I have two more children in the family… (Father, ref ID 16)

3.2.2 Health care facility

Inadequate surgical eye care facility, lack of eye screening programs for children and the protocols and procedures followed at the hospitals were identified as barriers.

For eye problems people go to the doctors in nearby town. They would give medicines and a pair of spectacles… with spectacles one has to be happy… Other than that there is no surgery service available close by. (Father, ref ID 4)

3.2.3 Environmental stressors

This includes issues related to distance to the hospital, transportation and the time taken for appointments contributed as barriers for seeking care. Most of the children's eye care facilities were located in larger towns and cities making it necessary for the families outside of these locations to travel long distances to access the services. Given the nature of surgical service and the number of follow ups required for the child pre and post op, parents and carers expressed challenges with various environmental stressors.

Because its hilly region not much transport availability, only there are smaller shared vehicles… and it is expensive… (Mother, ref ID 30)

4. Motivation and goals

The themes covered under this domain include the motivation of the parents and their intentions towards seeking services for their children.

A total of 10 themes were identified under this domain including 4 themes under Barriers and 6 themes representing enablers for accessing services and the Figure 5.8 shows the themes title and their order of importance.

Figure 5.8 Barriers and Enablers themes identified under the TDF domain 'Motivation and goals'.

The number within brackets indicates the number of quotes identified under each theme.

4.1 ENABLERS

The major themes identified as enablers under the TDF “Motivation, Goals and intentions” are ‘certainty of the intention’, ‘Intention’ and ‘Intrinsic motivation / service intention’. Some of the participants’ quotes are listed below for each of the identified theme in italics. Table 5.5 shows the interview excerpts reflective of the theme ‘Motivation, Goals and Intentions’ as an enabler.

4.1.1 Certainty of the intention

When the parents had clear intention to provide early treatment for their child, they accessed the services early despite having economic challenges in the families.

Everyone has different thoughts. I think that even if I am doing labour job, my child should not do this. He should do some better job. So I would forego my wages to bring my child for check up to make sure his eye sight is good. (Father, ref Id 5)

4.1.2 Intention

When the parents had positive intention towards the importance of eye sight for their child, they accessed the surgical services early.

It is a matter of the eyes. Every person will think that his child should be alright. (Father, ref Id 28)

4.1.3 Intrinsic motivation / service intention

Families whose children have gained vision after cataract surgery had clear intention to spread the benefits of early surgery in children among their communities.

When we go back with our daughter, many people come to see. So we will tell them that if your child has any eye problem, you should go to the nearest eye doctor. (Father, ref Id 16)

4.2 BARRIERS

Although there are more themes identified as enablers in this domain, parent’s motivation and intention also contributed to barriers. The major themes identified as barriers included ‘certainty of the intention’, ‘Priority’ and ‘Intention’. Table 5.6 shows the interview excerpts reflective of the theme ‘Motivation, Goals and Intentions’ as Barrier.

4.2.1 Certainty of the intention

Parents intended not to take their child for timely surgery. In particular, they were not certain about the need for early surgery in very young children, contributing to a delay in accessing surgical services.

First thing… I did not want my child to be operated upon as he is too small. If something happens … I had never before known or seen such a small child being operated. That's why I never thought of getting the surgery done. (Father, ref ID 4)

4.2.2 Priority

The other family priorities including looking after other children in the family and the fear of losing income when they have to visit the hospital for surgical services invariably delayed the access to cataract services.

They told to come after 2 months... we have to see ... there is no time, expenses too and we have to close the shop... it gets more difficult for other two daughters to go to school (Parents, ref ID 12)

4.2.3 Intention

When the parents are informed about uncertainty in the outcome of the cataract treatment, their intention towards cataract surgery was negative and hence caused delay in accessing the services.

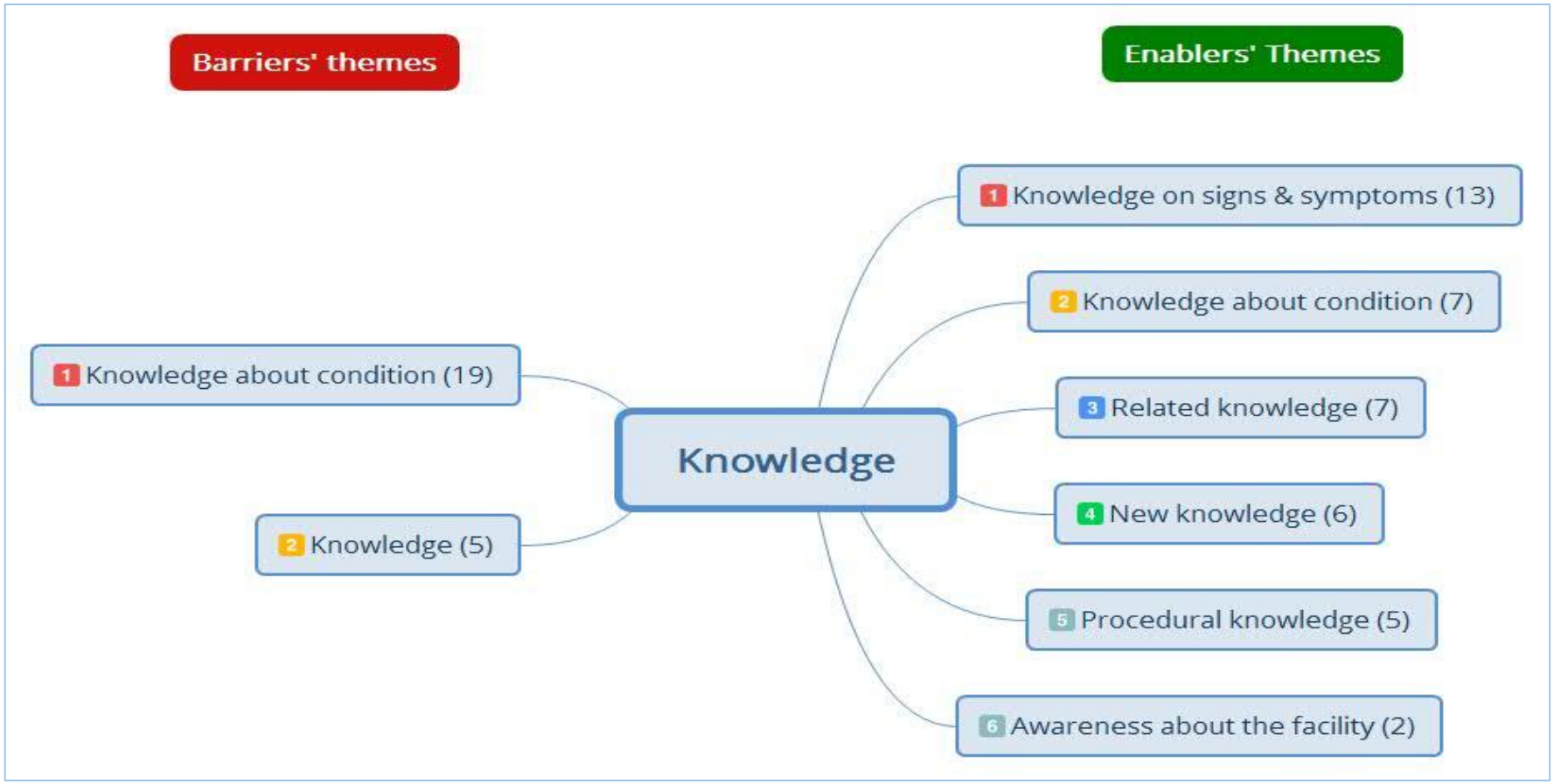
They said lens would be fitted. But they also said that the white spots won't go even after the lens is fitted inside. So I didn't go there again. (Father, ref ID 27)

5. Knowledge

Knowledge is a prerequisite for any behaviour and parents' knowledge about the child's condition has an impact on the uptake of services for the children. It includes, knowledge related to the condition, relevant information for children's eye health and the details of care required for the child.

A total of 8 themes were identified under this domain including 2 themes under Barriers and 6 themes representing enablers for accessing services. Figure 5.9 shows the themes title and their order of importance.

Figure 5.9 'Barriers and Enablers' themes identified under the TDF domain Knowledge.



The number within brackets indicates the number of quotes identified under each theme.

5.1 ENABLERS

The major themes identified as enablers under the TDF “Knowledge” were ‘Knowledge on signs and symptoms’, ‘Knowledge about condition’ and ‘related knowledge’. Some of the participants’ quotes are listed below for each of the identified themes in italics. Table 5.5 shows the interview excerpts reflective of the theme ‘Knowledge’ as an enabler.

5.1.1 Knowledge on signs & symptoms

Participants expressed a clear description of how cataract looks, what happens in the surgery and related knowledge on vitamin A rich foods to improve the eye health of the children. Some had acquired new knowledge from the hospital on the condition after the surgery.

Whenever we talk to the baby she looks around not facing me at the time baby was 4.5 months old... (Mother, ref Id 2)

5.1.2 Knowledge about condition

Cataract services were accessed sooner when parents had accurate knowledge about the disease and its treatment.

It’s not a good idea to delay the surgery. I feel the eye will get weaker if the surgery is delayed. It is better to get operated at the right time for a better vision. (Parents, ref Id 22)

5.1.3 Related knowledge

Parents having related eye health knowledge, especially the dietary requirements for maintaining good eye health, was associated with access to cataract services in children.

Yes, I feed them eggs, vegetables and yellow fruits. I have studied up to class X. I read in the books. (Mother, ref Id 23)

5.2 BARRIERS

Lack of knowledge about the condition was identified as a major barrier towards accessing cataract services for the children. The major themes identified as Barriers under the TDF “Knowledge” are ‘Knowledge about condition’ and ‘related knowledge’. Table 5.6 shows the interview excerpts reflective of the theme ‘Knowledge’ as barrier.

5.2.1 Knowledge about condition

Lack of knowledge about cataract in children among the parents was a major barrier to accessing childhood cataract services.

We didn't know about cataract. Now see some people have brown eyes. We used to think that they have white eyes. We didn't know that they had cataract. We came to know about it later (Mother, ref Id 20).

5.2.2 Related knowledge

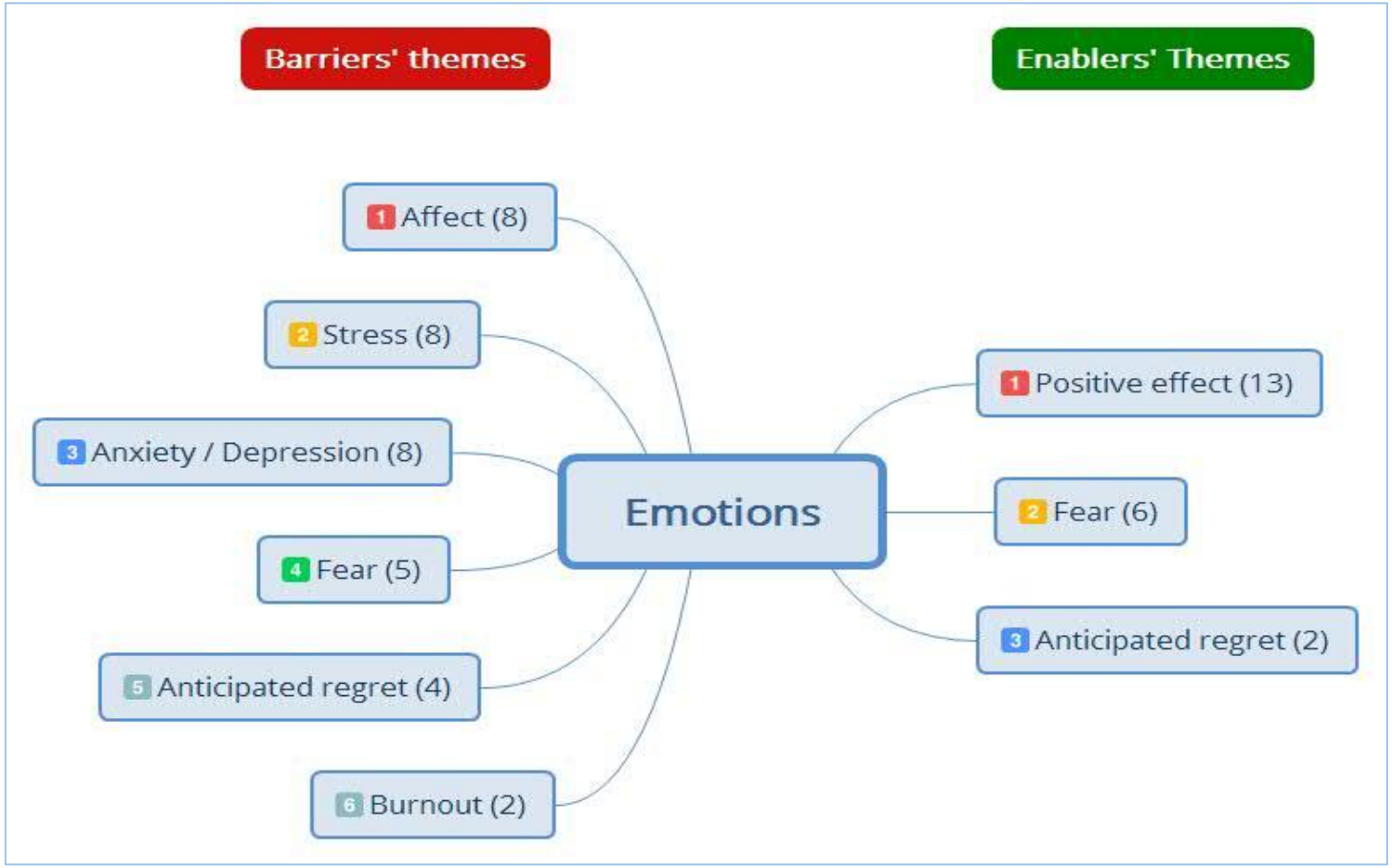
When the parents and families did not have any information on when to take the child to an eye hospital their access to the hospital services was delayed.

In the villages, many people don't know that children having eye problems should be taken to the hospital...There is no information… (Father, ref Id 16).

6. Emotions

The factors identified under this domain were complex, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with childhood cataract. A total of 9 themes were identified under this domain including 6 themes under barriers and 3 themes representing enablers for accessing services. Figure 5.10 shows the themes title and their order of importance.

Figure 5.10 Barriers and Enablers themes identified under the TDF domain 'emotions'.



The number within brackets indicates the number of quotes identified under each theme.

6.1 ENABLERS

The three themes identified as enablers under the TDF "Emotions" are 'Positive effect', 'Fear' and 'Anticipated regret'. All these three themes are responsible for both as enabler and as barrier for accessing cataract services in children. Some of the participants' quotes are listed below for each of the identified themes italics. Table 5.5 shows the interview excerpts reflective of the theme 'Emotion' as an enabler.

6.1.1 Positive effect

Family members' emotions played a major role in early access for cataract surgery in children. For example, anxiety about unoperated cataract and its consequences for their child had an impact on access to surgical treatment.

I realised that the child is not operated on time, she will go blind totally and the eye will become fully white. (Mother, ref Id 2)

6.1.2 Fear

Parents' fear of injury or complications after surgery affected the likelihood of them providing better care for their child's post cataract surgery.

I am always scared … I keep holding their hands that the eyes should not be hurt. Both my husband and I take a lot of care about our children. We don't let them go alone anywhere, we don't neglect about their medicines or anything. We keep them near us. (Mother, ref Id 20)

6.1.3 Anticipated regret

Parents feared that they might later regret delaying their child's cataract surgery, and such anticipated regret enabled accessing services earlier for their children.

In the villages…old people go for cataract surgery when it is 'ripe'…but this is a small child… I felt pity. I thought it is better to do it now in the beginning itself to save my child. (Father, ref Id 7)

6.2 BARRIERS

Parents'/ carers' emotions played a crucial role as barriers in accessing the cataract services in children. The major themes identified as Barriers under the TDF "Emotions" are 'effect', 'stress' and 'Anxiety / Depression'. Table 5.6 shows the interview excerpts reflective of the theme 'Emotions' as barrier.

6.2.1 Effect

There are other challenges for the child post cataract surgery which affect the child's education and other activities on a daily basis.

He went one day to school after surgery. He was wearing spectacles. Other children took his spectacles and it broke. Then I stopped sending him to school again. (Father, ref ID 15)

6.2.2 Stress

Families faced sources of stress in their daily lives, including factors that threatened well-being and even survival. These competed with the need for cataract surgery and contributed to delays in accessing surgical services for their children.

His father is doing labour job … Here we have difficulty in getting food and now all this … you should understand. There is no rain, only dry taps. No water. (Mother, ref ID 26)

6.2.3 Anxiety / Depression

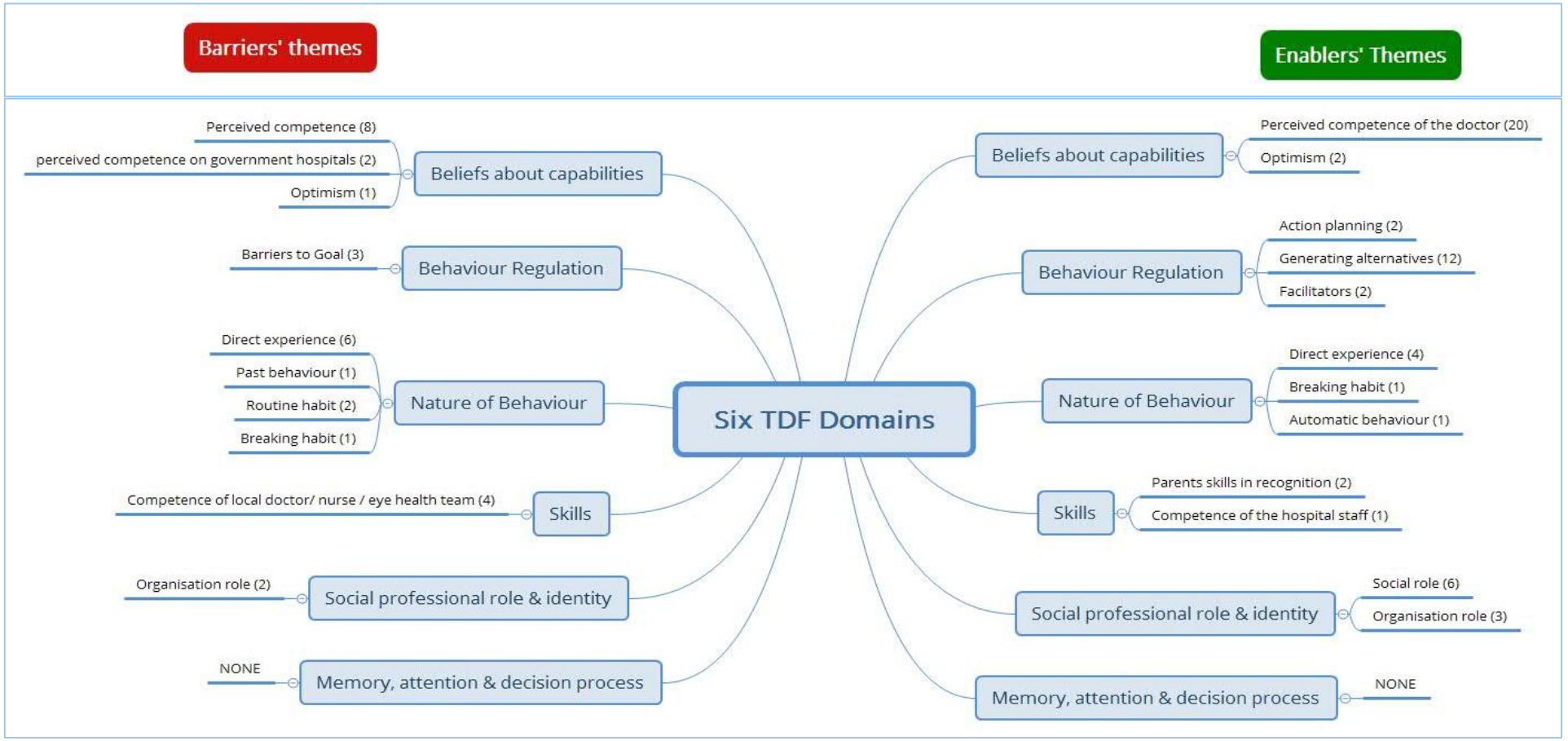
Parents suffered anxiety and depression when they heard about cataract in their child and the requirement for surgical intervention. The time take to overcome this contributed to a delay in accessing surgical services.

At the hospital where the doctor said that he has cataract. This was first time for us as no one in our family earlier has any such problem. The thing which should occur after 45 years of age had happened in such a small child … my family was shattered. Moreover, we had twins. So both the children had in both eyes. (Parents, ref ID 18)

7. Other Six TDF domains

Of the total 12 domains, 5 domains were identified with fewer themes and codes compared to the top 6 TDF domains discussed earlier in this chapter. There were no quotes identified for the domain ‘Memory, attention & decision processes’ in both barriers and enabler category. Figure 5.11 shows the summary of barriers and enablers themes identified under the six TDF domains.

Figure 5.11 Summary of Barriers and Enablers themes identified under the six TDF domains.



The number within brackets indicates the number of quotes identified under each theme under the relevant TDF domain.

7.1 'Skills' and 'Beliefs about capabilities'

The domains 'skills' and 'Beliefs about capabilities' are predominantly focused on the ability or proficiency acquired and about the ability that an individual has to provide childhood cataract services. These two domains have no direct relevance to the parents' however, the parents and the carers commented on the perceived skills and abilities of the doctor and the hospital staff on providing care for their children. For example, under the domain 'Beliefs about capabilities' 5 themes were identified including three as barriers and two as enablers. Some of the participants' quotes are listed below for each of the identified themes italics.

7.1.1 Perceived competence

Parents' and carers' perceptions of the hospital and the perceived competence of the doctors and the hospital staff acted both as barriers and enablers.

The doctors told that the surgery should be done immediately as with time the situation of the child would worsen. They showed me children aged as little as 4 months on whom surgery had been done and tried to convince me. They said that it is quite normal. After knowing all this, I became confident and went ahead with the surgery. (Father, ref Id 4) – ***Enabler***

Some doctors did not have the ability to diagnose cataract in children, and parents had to go to multiple hospitals for diagnosis and treatment, contributing to further delay in treatment.

She used to squeeze her eyes…… roughly at the age of three years. We thought it's not normal so we searched for a hospital….Just for the normal eye check-up …. We went to the nearest eye specialist and we went in the same week. They could not detect the cataract. They just gave spectacle prescription. We doubted and went to other hospitals … (Parents, ref ID 22) – ***Barrier***

In the government hospital only the doctor's consultation is free. You have to pay for the medicine. I could arrange some money in three years. Then I went to the hospital. We visited four times. Then they did the surgery… We visited one month after the surgery for follow up. Even after surgery she can't see properly in the operated eye. They called for the next surgery. But we didn't go ... (Mother, ref ID 30) - ***Barrier***

7.1.2 Optimism

Parents' belief towards other forms of medicines contributed towards delay in accessing the cataract surgery. An example comment:

People said about Ayurveda treatment. We had tried with Ayurveda in parallel and came to know that by applying Ayurveda medicines in the eyes cataract could be cleared... (Parents, ref ID 18) –***Barrier***

Three important codes were identified under the domain 'skills' as a barrier from the perspectives of the parents and carers. The first relates to a lack of skill among the local doctors in recognising cataract and this misleading parents who are seeking care. Secondly, the inability of the nurse to identify the cataract when the child was taken for immunisation at regular intervals, and thirdly, the capability of the school eye screening professionals to detect cataract. Even though the child was screened many times during the school eye screening the team did not refer the child immediately to the hospital for surgery. The parents' interview excerpts reflective of the domain 'skills' as barrier is reported in Table 5.6.

7.2 Nature of Behaviour

This domain was focused on the parents' / carers' experiences of behaviour pattern. For example, if any family relative had a positive experience with the hospital or with their treatment from a specific facility, this may influence parents positively towards accessing the services. Similarly, any negative experience in the past within the family or with their relatives acted as barrier for seeking care. For example, occlusion therapy advised post-surgery was found to be an impediment to the mother, who felt it was challenging and unfeasible. (See excerpts in Table 5.6 under the domain 'Nature of Behaviour')

However, parents accessed a particular facility knowing that they can avail free treatment, based on experience of family elders who had previously had cataract surgery at the same facility.

7.3 Behaviour regulation

This domain focuses on the ways and means of bringing behavioural change at the community level. Parents' and carers' suggestions towards bringing change in the community have been coded under this category.

Under the enabler category, three themes were identified including 'action planning', 'generating alternatives' and 'facilitators'.

Meetings can be arranged in the village to discuss these issues. The meetings could be arranged through the village head or can be conducted in the village primary school where all the parents should be called. These things should be discussed in that meeting. If people are told in such meetings, many people will be aware. (Parents, ref Id 10)

In the villages eye camps are held for older people. Doctors come there. They identify the cataracts and take them for surgery. The camp is held once in a year. But they do not check the children. Nobody knows or understands…. Yes it would be very good to check the children in the camps. No need to go here and there. (Father, ref Id 11)

For coming directly some kind of link is required …where to go, what to talk…? Say if had come alone, I would have been confused… what to do, where to go … So when I came here through camp, I had a slip with me where it was written 'contact counter no 4'. So I went to the counter no 4 where the registration was done and then whatever was required these people went ahead with their work and prepared the file. (Father, ref Id 5)

To summarise, this study has identified many enablers and barriers associated with the access of childhood cataract services in India. The three major Barriers and Enablers and the main themes which emerged from the analysis are listed below.

Barriers	**Enablers**
1. Environmental context and resources 1.1. Economic 1.2. Health care facility 1.3. Environmental stressors 2. Beliefs about consequences 2.1. Consequents 2.2. Beliefs 2.3. Attitudes 3. Social influences 3.1. Social norms /culture 3.2. Social pressure 3.3. Social support	1. Social influences 1.1. Social support 1.2. Social norms / culture 1.3. Change agents 2. Beliefs about consequences 2.1 Attitudes 2.2 Reinforcement 2.3 Values 3. Motivation, goals and intentions 3.1. Certainty of intentions 3.2. Intention 3.3. Intrinsic motivation

Table 5.5 Sample quotes referring to enablers, sorted by TDF Domain

(P – Parents; M – Mother; F – Father; GP – Grandparents; FG – Family group)

TDF Domain	Identified Theme	Frequency (*n* transcripts)	Interviewees (Roles, *n*)	Sample Quotes
Beliefs about consequences	Outcome Expectancies	6	GP (2), P (3), M (1)	It's not a good idea to delay the surgery. I feel the eye will get weaker if the surgery is delayed. It is better to get operated at the right time for a better vision. (ref Id 22) I asked the doctor. He said that it happens to some new-born babies. He suggested to get the surgery done at the earliest. Otherwise the problem may increase. (ref Id 29)
	Attitudes	17	GP (1), P (8), M (1), F (7)	We felt … but, then we thought it is about the eyes and eyes are everything. So it is necessary. My elder brother also came. We quickly took the decision to go ahead with the surgery and admitted her. (ref Id 10) Surgery should be done at the earliest. Age should not be a barrier. Whenever there is a problem, surgery should be done. (ref Id 10) Yes-yes, it is very good to check the eyes of the children. I am thinking about my other children who are ok now… but there is no harm in getting a routine test done. (ref Id 6)
	Reinforcement	11	GP (1), P (3), M (1), F (6)	The doctors told that the surgery should be done immediately as with time the situation of the child's eye sight would worsen. They showed me children aged as little as 4 months on whom surgery had been done and tried to convince me. They said that it is quite normal. After knowing all this, I became confident and went ahead with the surgery. (ref Id 4) Yes, I was afraid. Such a small child… but then the doctor said that if surgery is not done early then his second eye might also get affected. This eye might get totally useless. (ref Id 29)
	Beliefs	3	GP (1), F (2)	Cataract is not god's curse. In many people after cataract surgery they can see. I believe in god and pray every day in the morning and I believe god blesses us…(ref Id 1)

	Perceived risk/threat	8	GP (1), P (3), F (4)	We wanted to get it done at the earliest possible. I also heard that cataract bursts. So we wanted to do it at the earliest. (ref Id 10) Yes, without delay surgery should be done… the problem might increase. It is possible that it might not be cured by surgery even. (ref Id 16)
	Priority	9	M (3), P (2), F (4)	Yes, I think there is still some treatment to be continued after surgery. We have to come here a few times for her check-up. Well, even if it is a problem coming for follow up, I can't ignore as it's my responsibility. (ref Id 10) He goes to school. Today he had a test. I gave a leave application to the school and brought him today. I thought this is important and should be done at the earliest. Earlier also he had to skip school... (ref Id 23)
	Anticipated regret	1	F (1)	If he cannot see then I must get him treated. Otherwise when he grows up he will blame us that we spoiled his eye…(ref Id 27)
	Sensitisation	8	M (2), P (3), F (2), GP (1)	Meetings can be arranged in the village to discuss these issues. The meetings could be arranged through the village head or can be conducted in the village primary school where all the parents should be called. These things should be discussed in that meeting. If people are told in such meetings, many people will be aware. (ref Id 10) We can also conduct awareness programs during the fairs at the village. Health exhibitions can be conducted and knowledge on childhood cataract could be given to the villagers. (ref Id 10)
	Appraisal / review	3	M (1), P (2)	Before the surgery if we would keep anything, say a toy… in front of them, they would not react. But after the surgery when the bandage was removed, we put a pen in front of him and he immediately grabbed the pen! That was probably the biggest moment of my life … That something is visible now. At that point I felt that we were going in the right direction... (ref Id 18)
Environmental context and resources	Health care facility	4	P (1), F (2), GP (1)	So when I came here, I had a referral slip with me from the community screening, where it was written 'contact counter no 4'. So I went to the counter no 4 where the registration was done and then whatever was required these people went ahead with their work and prepared the file. (ref Id 5)

	Person X environment interaction	9	P (3), F (4), M (2)	Well, previously there was problem of education in the village. But now people are getting educated and if there is a problem, people do go to hospital. There is nothing such as applying home remedies (ref Id 10) Yes, some people don't know that even small children could get cataract. Now in our village everyone has come to know. This should be publicized. Now that we know this, we have to tell in our village… also if it comes on TV or newspaper it would be useful. (ref Id 14)
	Environment	3	F (1), GP (2)	Publicity can be done through the TV. In villages also everyone watches TV. It is not possible to go to every house and do this. Now if someone comes to us… we can suggest to go to the doctor. Other way is to go to the villages and tell people…(ref Id 29)
	Economic	1	F (1)	Yes, I will come as many times the doctor calls for follow-up. Yes, my daughter and wife both come with me .I don't care about the expenses. INR 100 to come, another 100 to go. It takes about two and half hours by bus and three hours by auto. (ref Id 7) The doctor said that it was Cataract. No, we didn't hear about it occurring to new born babies. Then we searched it on the internet and came to know that it happens to new born babies too. (ref Id 29)
Social influences	Social support	39	P (14), F (14), GP (6), M (5)	Our father or uncle is there… They are the elders. In case of this child, her grandparents were also involved along with other family members and a common decision was made. (ref Id 3) In the rural areas people don't have money. So, major decisions are taken after the family members sit together and decide on where the money will be arranged from and how. Sometimes neighbours and / or relatives are also involved. (ref Id 3) I had heard from many people that there are good eye specialists in this town. I tried to find out who knows about this place and took his support and brought him along with me to this hospital. (ref Id 4)

	Social norms / culture	19	P (8), F (3), GP (2), M (6)	There are some people who believe in taking village medicines, jari-buti [herbal extracts] … some people. But nowadays mostly people are educated, they know and go to the hospital. (ref Id 14) We make no difference whether it is a boy or a girl. Our daughter does not have any problem. But we got her examined. (ref Id 18) We thought about her career … Better if it is done in the right age. It is very important for a child. Especially a girl child. (ref Id 22) We both together take decisions in our family. In other families, in general the father is busy and away from home. The mother spends more time with the child and takes good care. So she could decide. (ref Id 22)
	Change agents	10	P (5), F (2), GP (2), M (1)	You (The hospital) are here. But we come to you. So your publicity will happen through us. We go back and tell people that the doctors at this hospital are good, it has the best facilities. (ref Id 16) See, education has to be increased. As they (the parents) get educated, they will change, their thinking will change. (ref Id 19) It is necessary to get an eye examination done …even if the child eyes are normal. In our country during the time of birth itself it should be done once by the doctor in the hospital. (ref Id 29)
Emotions	Fear	6	P (1), F (2), GP (2), M (1)	I had a doubt whether it will get cured or not? Just thought of quickly going to the hospital. (ref Id 1) I felt scared…I thought his future should not be wasted. I asked the doctor again. He said that a lens will be fitted and it would cause no harm. Then, I said ok. Let the surgery be done… (ref Id 18) I had heard from people that if cataract is not treated the child can become blind. I got afraid and came straight to the doctor. (ref Id 19)

	Positive effect	13	P (5), F (5), M (3)	I felt very bad. Previously only older people would get it. Now it has started among young children as well. So I thought that I have to get him operated. . (ref Id 14) I realised that the child is not operated on time, she will go blind totally and the eye will become fully white. (ref Id 2) My children who use to seeing with crossed eyes could see straight now. Others seeing only things up close earlier, could also see the distant things. I feel relieved that my children are able to see well than before. (ref Id 20)
	Anticipated regret	2	P (1), F (1)	Not only once. I would suggest yearly once children eyes and all other check-ups should be done. If we ignore and think that everything is fine, it might happen that when there is really a problem we would regret that we should have done it before and control it. (ref Id 18) In the villages…old people go for cataract surgery when it is 'ripe'. And then this is a small child… I felt pity. I thought it is better to do it now in the beginning itself to save my child. (ref Id 7)
Skills	Parents skill in recognition	2	P (1), GP (1)	Her mother first noticed something white in the eyes. But I was avoiding thinking that it would go away on its own …(ref Id 10) Mothers can closely watch the child for his eye movements and identify if there is any eye problem. (ref Id 29)
	Competence of the hospital staff	1	P (1)	If we come to know about anyone with eye problem, we will suggest them to come to this hospital. We have seen that the employees here are very helpful by nature. I have never faced any problem here. Once you reach here, get yourself registered at the counter, then you don't have to worry for anything further. This is my experience here. (ref Id 10)
Social professional role and identity	Social role	6	P (5), F (1)	We keep roaming around the villages. So we need to talk about this. So that if anyone is suffering with eye problems, she/he should be taken to the hospital at the earliest. Home remedies should not be used. (ref Id 10) We will go and inform the villagers. Actually this is how it happens in the villages. Whoever knows, has to give proper suggestions or accompany to come here. (ref Id 3)

	Organisation role	3	F (1), P (1), GP (1)	There should be camps for the children so that the parents would become aware and the children would get care. It will be good for all. Such camps are never organized. People don't take children for examination on their own. Because they have no idea that children could have eye problems. They can't think of it. (ref Id 18)
Motivation and goals	Certainty of the intention	29	F (10), P (11), GP (3), M(5)	The first doctor whom we met had told that he has got cataract since birth. After knowing this I have concentrated only on his treatment so that he could be able to see well. (ref Id 4) There are no pressing issues for me other than my child now. I will bring my child for follow up as per the instructions(ref Id 4) Everyone has different thoughts. I think that even if I am doing labour job, my child should not do this. He should do some better job. So I would forego my wages to bring my child for check up to make sure his eye sight is good. (ref Id 5) I thought that my daughter is young now. If she gets good treatment, her life will be better. That's why we decided about this place because no other place would be better than this. God willing, I hope that we won't need to bring her here again. (ref Id 6)
	Intention	18	F (6), P (6), FG (2), M(4)	We saw in six months. But actively we started working on it when she started walking at about 9-10 months of age. (ref Id 10) We have been told to come every fifteen days. We did not say no. There should not be negligence from our side. His life has to be successful …(ref Id 14)
	Intrinsic motivation / service intention	8	F (3), P (3), M(2)	When we go back with our daughter, many people come to see. So we will tell them that if your child has any eye problem, you should go to the nearest eye doctor. (ref Id 16) Parents should bring the children here for consultation. Yes the camps should be organized frequently … so that other children should not suffer what my children suffered. Whatever has happened with my children should not happen to others. (ref Id 20)

	Stability of intention	2	P (1), M(1)	I don't know about other things. But it is very important eyes to have regular check-ups, drops etc. We come here once in two months. But in between also if we notice even slight difference or abnormality we get in touch with doctor Sir over phone/WhatsApp and follow his suggestions. If required, we even pay a visit. (ref Id 18)
	Commitment/ Motivation	2	P (1), M(1)	90% of the responsibility lies with us as parents, we have to take the responsibility and take the child to the doctor in time and take the treatment and follow the instructions of the doctor. (ref Id 2)
	Routine	1	M (1)	Parents should notice if the children have any difficulty in reading. If the child is keeping the book too close while reading. If the child is having any problem in reading they should immediately take him to the hospital. (ref Id 23)
Nature of behaviour	Direct experience	4	P (2), F (1), GP (1)	I know in this hospital we can get free treatment so, I came here. (ref Id 1) Our older people keep on coming here. So, I got the information. No, our elders... his grandfather has come here. (ref Id 13) Never we will get arrange marriage for our children within the relatives. Now that we know … We did because we didn't know. (ref Id 18)
	Breaking habit	1	F (1)	At home they were saying to put something or other …it might work … desi [indigenous] medicines …No, they told me to go and get it. But there was no guarantee. So I said what the use is if it doesn't work. So I didn't use any. (ref Id 15)
	Automatic behaviour	1	GP (1)	In our country during the time of birth itself it should be done once by the doctor in the hospital. (ref Id 29)

Behaviour regulation	Action planning	2	P (2)	Meetings can be arranged in the village to discuss these issues. The meetings could be arranged through the village head or can be conducted in the village primary school where all the parents should be called. These things should be discussed in that meeting. If people are told in such meetings, many people will be aware. (ref Id 10) We can also conduct awareness programs during the fairs. Health exhibitions can be conducted and such knowledge could be given. (ref Id 10)
	Generating alternatives	12	P (4), F (6), GP (1), M (1)	Yes, some people don't know that even small children could get cataract. Now in our village everyone has come to know. This should be publicized. Now that we know this, we have to tell in our village. Those who are going to other villages should tell the same … That the small children could have problem. Get them checked. People will come to know …. Also if it comes on TV or newspaper it would be useful. (ref Id 14) I think if it comes in the newspaper many people will come to know. I can tell in my own village. But there are other villages far away …(ref Id 14)
	Facilitators	2	F (2)	For coming directly some kind of link is required …where to go, what to talk…? Say if had come alone, I would have been confused… what to do, where to go … So when I came here through camp, I had a slip with me where it was written 'contact counter no 4'. So I went to the counter no 4 where the registration was done and then whatever was required these people went ahead with their work and prepared the file. (ref Id 5) In general hospitals it happens like – go to counter number 3 or go to counter number 4 … and the person goes around in circles. But here you don't have to do anything. Even the file is also carried by a person. He will make you sit down. After you are seen, the file goes to another place… (ref Id 6)
Knowledge	Knowledge about condition	7	P (3), F (1), GP (2), M (1)	There was this white coloured thing in his eyes… like a film. So, I could understand that it could be cataract. Got him examined and was confirmed that it was cataract. (ref Id 14) It's not a good idea to delay the surgery. I feel the eye will get weaker if the surgery is delayed. It is better to get operated at the right time for a better vision. (ref Id 22) Yes I knew… It could happen in any age. Some get it in the old age, some get it young. Some have it from birth. The white spots start coming in the eyes. (ref Id 7)

	Procedural knowledge	5	P (3), M (2)	Now we have to implant the lens and this is the first step of the treatment and we need to go forward. Doctor will tell us what needs to be done in the future. (ref Id 2) We would provide her with sun-glasses and clean her eyes with clean soft cotton for hygiene. (ref Id 22)
	Related Knowledge	7	P (3), F (1), GP (2), M (1)	Spinach, carrot, papaya are good for the eyes. They prevent night blindness. We also tell the pregnant mothers to eat nutritious food like milk, curd, rice, and pulses etc. which are available normally at home. (ref Id 10) Fruits like carrot, papaya, spinach and other vegetables… dry fruits…milk… since the time they have started eating, we give them all of these. I know that these are good for the eyes. (ref Id 18)
	Knowledge on sign and symptoms	13	P (1), F (6), GP (2), M (3), FG (1)	When he used to go out in the sun, he would close his eyes with his hands. (ref Id 19) Whenever we talk to the baby she looks around not facing me at the time baby was 4.5 months old... (ref Id 2) He ….always squeezes his eyes... when he goes out in the sunlight. (ref Id 24) Unable to see and the black area in the eyes would always 'dance'. The child would frequently close the eyes. (ref Id 5) Children cannot identify the problems. We only have to see. If they are holding things properly. If not then we should understand that the child has problem and should take him to the doctor. (ref Id 7)
	Awareness about the facility	2	P (1), F (1)	For three four years I know about the hospital … The villagers know about it. They told to come here. So I was coming by myself… not through the camp. (ref Id 15) We searched on google. For the best doctor for cataract surgery. Thus we came to know about this Hospital. (ref Id 22)
	New knowledge	6	P (2), F (3), GP (1)	Even younger children … 2 months or even 2 days old children can have eye surgery…the doctor told us. (ref Id 18) We didn't hear about it occurring to new born babies. Then we searched it on the internet and came to know that it happens to new born babies too. (ref Id 29)
Beliefs about capabilities	Optimism	2	P (1), M (1)	I bring her here for check-up and tests. All four of my children come here for check-ups… (ref Id 20)

	Perceived competence of the doctor	20	P (5), F (11), M (4)	The doctor examined them on our first visit and assured that there is nothing to worry. There are various reasons for this. But it can be solved up to some extent through proper treatment. He also assured that if we follow what is suggested then there is maximum chance that they will be fine. We have no idea about how cataract is managed… If we are consulting with the doctor, we have to believe on him. (ref Id 18) Whatever the doctor advise we have to do, doctors have the Jawabdhari [responsibility] so we need to follow their advice. (ref Id 2) We have to act according to doctors' advice and it's our duty to take care of the child. (ref Id 2) No, we didn't have any idea about when the child has to have eye surgery. Whatever the doctor suggests we would do that. This is the general thinking. Whatever the doctor says, people follow that. (ref Id 3)

Table 5.6 Sample quotes referring to barriers, sorted by TDF Domain

(P – Parents; M – Mother; F – Father; GP – Grandparents; FG –Family group)

TDF Domain	Identified Theme	Frequency (*n* transcripts)	Interviewees (Roles, *n*)	Sample Quotes
Beliefs about consequences	Outcome Expectancies	3	P, GP, FG	It is good to go for surgery if he is cured. Surgery should do good … but they said that the white spots won't go in his eyes. So why to go for the surgery …. That's why I didn't go again (ref Id 27) Now that she does not have the eye which she originally had during her birth, my concern is that she should not have any problem after 5-10 years. She is a small girl. There should not be any issue when she grows up. (ref Id 3) No…. we never thought the child should go for an eye check-up when there is no problem... Only if there is a problem, children should be taken for check-up. Otherwise not necessary. (Ref ID 10)
	Attitudes	10	P (4), F (3), M (2), WF(1)	Only when there is problem in the child we will go to the doctor. If the problem is not visible, we will wait till the problem is visible and if any one identifies it we will go to the eye doctor only. (Ref Id 2) We are village folk. If the child does not have any problem, we don't do anything. Only if the child has a problem we take him to the doctor. We don't have any eye doctor nearby our house… (Ref Id 3)

	Beliefs	16	P (1), F (11), M (1) GF (2), GP (1)	It is about the faith in god… if god can cure, let him cure… no need to worry (Ref Id 13) Baba [local priest] gave him some medicine and suggested to put it on the eye lashes… so that the cataract will get cured. We did for 2-3 months and it didn't work. (Ref Id 13) From his birth he had a white spot in the eyes. We noticed within one to two weeks of birth. He was delivered in a hospital and both I and his mother noticed it. I came to know that this is cataract. But I didn't think of doing anything because since he had it from birth it was a curse of God and nothing could be done about it. (ref Id 31)
	Critical incidents	5	P (1), F (3), WF (1)	She had problem since beginning. She had trouble in seeing. She used to see like this bending her head on one side and squeeze her eyes always. Then we showed her to a local eye doctor. He did not say anything. He only gave number for spectacles. But her discomfort continued. After that we showed her to another doctor who gave medicines to eat… We did all this in our area, where we live. Our local doctor...It is within Delhi… (ref Id 6)
	Unrealistic optimism	5	F (2), M (1) WF (1), GP (1)	It happened since he was born. Now he is 4 years old. It is there since four years. We kept on thinking that it will go away, it will be cured. We kept on going to "babaji's place". People recommend this place to visit… to get cured. That's it … and the time kept passing on …(Ref Id 13)
	Regret	2	P (1), GP (1)	There was no money so he went out for two months and earned money. Then the surgery was done. If we had money, could have done it in the beginning itself when we came. (ref Id 14) Yes… patching exercise needs to be done 3-4 times a day….. We also feel that it was probably a wrong decision to do the surgery early. Had it been later, possibly the lens could have been fitted. (ref Id 29)

	Consequences	19	F (5), M (6) P (4), GP (4)	School was stopped now for some time … yes, he has gone school 2-3 days. He was wearing spectacles. Other children took his spectacles and it broke. Then I stopped sending him again. (ref Id 15) If we tell him to bring something, he is unable to pick it up … I felt very sad but he is too small so we didn't go for the surgery. If he rubs the eyes he might hurt himself. (ref Id 26) We are poor people. We somehow fill our stomach through labour work. How would we know? Local Doctor Sahab told that it will take time. So we came back thinking that let him grow up. Then we will do. (ref Id 26) Most important is cleanliness. Many are living in a dirty place and it can cause infections in the eyes. (ref Id 22)
	Not a priority	7	F (1), M (3) WF (1)	She had it even before but our family did not notice it …She was in year VIII. She used to live in the hostel. She informed us that she can't see properly... But we laughed it off … she was so young. How could she see less? Nobody understood. Not even me. When it increased, she told us again after 2 months... Then we showed her to the doctor there. (ref Id 16) Four of my children have got cataract. I didn't understand during my first child. She was fine until the age of five years. Afterwards she started having crossed eyes. She would see diagonally. Everyone at home would laugh… What kind of disease is this … She got habituated like that … Then later we consulted the doctor. (ref Id 20)

	Perceived risk/ threat	6	F (2), M (3) P (1)	"The lens will break. That's why we didn't do it out of fear. We thought that once he grows up we will do it. We are afraid that the lens might break. (ref ID 26)
	Review	1	M (1)	In the government hospital only the doctor's consultation is free. You have to pay for the medicine. I could arrange some money in three years. Then I went to the hospital. We visited four times. Then they did the surgery. The surgery was done for the nerves. We visited one month after the surgery for follow up. Even after surgery she can't see properly in the operated eye. They called for the next surgery. But we didn't go… (ref ID 30)
Environmental context and resources	Economic	33	F (13), M (12) P (7), GP (1)	Yes madam. I do labour job. It is labour job. If you go, you get (wages), if you don't go, you don't get... (ref ID 16) It took months to recognise the problem in my child. We took the child to the general hospital they asked huge money for the surgery as we don't have good financial condition, we couldn't do. We had only yellow ration card which is eligible for only some concession. (ref ID 2) It would take about 4-5 years to arrange the money, Rupees five thousand. Even though the surgery is free, they asked us to pay INR 2700 for giving injection by a special doctor for pain less (anaesthesia). (ref ID 30) She will go to someone else's house. She is not mine. Now tell me where would I get her married? Our days are over…. If we don't do for the girl, who will do for her. No one will do. We don't want to sit with the problem. But we are helpless because of money. What to do …(ref ID 8)

	Health care facility	21	F (10), M (8) P (1), GP (2)	For eye problems people go to the doctors in nearby town. They would give medicines and a pair of spectacles with which one has to be happy. Other than that there is no surgery service available close by. (ref ID 4) For coming directly to the hospital some kind of link is required … where to go, what to talk…? Say if had come alone, I would have been confused… what to do, where to go … I will be lost in this big hospital(ref ID 5)
	Environmental stressors - Mobility/ transport	5	F (1), M (2) P (2)	Because its hilly region not much transport, only there are smaller shared vehicles. It costs 100 rupees up & down. Another 10-15 rupees to go to the government hospital. (ref ID 30) No difficulties except that coming by train becomes a bit difficult at times…. From that far. We have to come in the general compartment. Sometimes it is crowded, sometimes it is comfortable…(ref ID 14)
	Environmental stressors – Distance	3	F (2), M (1) P (2)	Yes, it is too far… It takes four hours from Mahbuba to here… Another three hours from Khajuraho. Yes, and it is another 12 kms by vehicle from Khajuraho. (ref ID 13)
	Environmental stressors – Time	3	F (2), WF (1)	If there is no problem, who would go for check-up. Who has so much time nowadays…..Only when there is a problem people are ready to go anywhere. (ref ID 28)
	Nature of Environment	2	F (1), P (1)	Most important is cleanliness. Many are living in a dirty place and it can cause infections in the eyes. (ref ID 22)

	Person X environment interaction	8	F (5), M (1) P (2)	Many in my class [a child with cataract] tease me calling me 'blind'. (ref ID 30) We do not take much care about our children's eyes. When they watch TV we don't care about what the distance should be, we don't care about how much time the children should watch TV, we are not careful about the food that children should eat so that their eyesight should not be weak. (ref ID 6)
	Alternative medicine and Traditional practices	3	F (1), WF (2)	They just said that he got injured in the eye. There were white spots in the eyes. It has reduced. For the last one month I have stopped the drop and continuing with the 'desi' (indigenous) treatment in the village. It's a jari (herb) I don't know… there is one 'baba'. He gives... (ref ID 27) For minor condition we do not have an option other than to go to the village doctor. Only when something goes wrong, people become cautious and avoid going to village doctor. (ref ID 4)
Social influences	Social support (lack of concern/ misguidance/ inappropriate advice etc.)	7	F (3), M (3) P (1)	I noticed his movements and asked my parents about it – why he walks like that … he would look as if he has crossed eyes. My parents said that your child has crossed eyes that's why he walks like that. They said that it is a good sign of luck (ref ID 4)
	Social identity	3	P (3)	There are people who think like that … even nowadays in my area. Boys receives better care than the girls. (ref ID 18)

	Social pressure	8	F (2), M (3) P (2), WF (1)	My daughter would look always downwards, never upwards. I would say there must be some reason that she never looks upwards. But elders at home and many people said that this happens to the children and it will be cured later. (ref ID 10) It happened since he was born. Now he is 4 years old. It is there since four years. We kept on thinking that it will go away, it will be cured. We kept on going to “babaji’s place” [local priest]. People recommend this place …… all problem gets cured… Yes, people were telling that it will get cured if visit to babji's [Local priest] place... (we were) thinking … Good if it gets cured…(ref ID 13)
	Power / hierarchy	7	F (3), M (2) P (1), WF (1)	When he would drink milk, I noticed white spots in the eyes. I told to my mother in law. She said it happens in children. I said no but she was the head (in the family)… and she didn’t agree. (ref ID 14) I have accumulated the money for his operation … Six thousand rupees. But my in laws were not allowing us to go for surgery as everyone feels the child is too young... (ref ID 26)
	Social norms / culture	13	F (5), GP (1) P (6), WF (1)	One reason which I feel could be that I married within relations. My father and grandfather also had married within the relations. I am the third generation that has married within the relations. This could be the reason... (ref ID 18) Among people who are not educated there is a difference in how they treat boys and girls but it’s the same among the educated families. (ref ID 22)

	Parental negligence	6	F (3), GP (1) M (2)	She has the problem from May-June. She had it even before but our family did not notice it – what was there in her eyes. She was in class VIII. She used to live in the hostel. She told also. But we laughed it off …… she was so young. How could she see less? Nobody understood. Not even me. (ref ID 16) Whenever we advise the parents with the children with cataract or squint they refused to go to the eye hospital and they said it will cure on its own. So we don't force them. (ref ID 2)
	Organisation norms	2	F (1), M (1)	I always listen carefully to any announcement that is made in our area. So that if there is a camp I can take my children for check-up. But the camp was organised only after four years (ref ID 20)
	Conflicts	2	F (1), M (1)	Yes, we have given all immunisation to him. The nurse didn't say anything about his eye problems. He is eight years now and he does not go to school. He used to go. But due to this problem he could not see and stopped going. (ref ID 31)
Motivation and goals	Certainty of intention	11	F (4), P (4) M (3)	If hospital facilities were available, even girls would also get treatment. Otherwise … Curse of God …(ref ID 31) First thing… I did not want my child to be operated upon as he is too small. If something happens … I had never before known or seen such a small child being operated. That's why I never thought of getting the surgery done. (ref ID 4)
	Priority	7	F (3), P (2) M (1), GP (1)	They told to come after 2 months... we have to see ... there is no time, expenses too and we have to close the shop... it gets more difficult for other two daughters to go to school (ref ID 12) Hospital do a lot of follow up. Now, the parents should also understand that it is their responsibility and is beneficial for them to follow what is advised as a priority. (ref ID 19)

	Intention	6	F (3), M (1), WF (2)	I thought it would be cured by homeopathy and treated for 3-4 months. (ref ID 28) They said lens would be fitted. But they also said that the white spots won't go even after the lens is fitted inside. So I didn't go there again. (ref ID 27)
	Goals and motivation	3	P (1), M (1), GP (1)	Two times camp was organized. I got two of my children treated through the camp. I didn't go to hospital directly as I had no money.(ref ID 20)
Emotions	Effect	8	F (3), M (3), GP (2)	He went one day to school after surgery. He was wearing spectacles. Other children took his spectacles and it broke. Then I stopped sending him to school again. (ref ID 15) I don't feel good that a lens could not be fitted. Doctor has suggested exercise. But he [the child] doesn't let us to get him to do those…as he is unable to see with one eye at all. The doctor didn't tell us about it earlier the lens couldn't be fitted … we don't know what the problem in putting the lens… now he needs to use contact lens permanently. Until now he must have lost 10-15 lenses (ref ID 29)
	Stress	8	F (5), M (2), P (1)	His father is doing labour job … Here we have difficulty in getting food and now all this … you should understand. There is no rain, only dry taps. No water. (ref ID 26) My husband never takes any responsibility for the child and home. He lives in his own world and he needs only money for his drinking... (ref ID 30)

	Anxiety/ Depression	8	F (1), M (3), P (3), GP (1)	I felt very bad. I cried a lot for two-three days. Such a small child, what has happened to her eyes, how we would manage … we thought all these and cried. (ref ID 10) At the hospital where the doctor said that he has cataract. This was first time for us as no one in our family earlier has any such problem. The thing which should occur after 45 years of age had happened in such a small child … my family was shattered. Moreover, we had twins. So both the children had in both eyes. (ref ID 18)
	Fear	5	F (2), M (2), P (1)	"The lens will break. That's why we didn't do it out of fear. We thought that once he grows up we will do it. We are afraid that the lens might break. (ref ID 26) I felt very scared about surgery… Because she is very young …(ref ID 12)
	Anticipated regret	4	F (1), M (1), P (1), WF (1)	We felt very sad. She is so young and she has got cataract! What would happen if we get her married? Problems can arise. (ref ID 16) I didn't realise so far…If he cannot see then I must get him treated. Otherwise when he grows up he will blame us that we spoiled his eye. (ref ID 27)
	Burnout	2	M (1), P (1)	Coming by train becomes a bit difficult at times…. From that far. We have to come in the general compartment. Sometimes it is crowded, sometimes it is comfortable… Money … well … we are poor anyway … we have to arrange for money by doing labour work …There was no money so he (father) went out for two months and earned money. (ref ID 14)

Skills	Competence of local doctor/ nurse/ school eye health team	4	F (3), GP (1)	We also asked the doctor with whom we regularly consult for him whether he has any problem in the eyes. He said no there is nothing to worry. No. They say that new born babies have blurred vision up to 20 days …..(ref ID 29) Yes, we have given all immunisation to him. The nurse didn't say anything about his eye problems. (ref ID 31)
Social professional role and identity	Organisation role	2	M (1), F (1)	For my third child, I came through the camp and came to the hospital with their prescription. They said surgery was required. I said ok. Then I enquired about the younger child at the hospital who also had cataract… I asked madam about the expenses. She said minimum twenty-five thousand. So I had to sit back because I cannot arrange so much money. Now again the camp has been organized after four years. I showed him there. (ref ID 20) Camps are organized in our area. But these are done once in two months or six months or one year (no regularity). The second thing is, in these camps they don't talk about children's problems. Mostly the elderly people queue up and they do not pay attention to the children. (ref ID 6)
Behaviour regulation	Barriers to Goal	3	GP (1), F (2)	Now that surgery is suggested, then if spectacles are required after surgery…. The child can't wear spectacles or will not be able to protect it. So it will be better to do the surgery after 5-6 years. (ref ID 5) In the school eye screening they checked several times in the school and said that there will be a camp organised soon and the doctor will come to the camp and needs to be examined by the doctor only. He goes to school but no one clearly said anything about his problem, so we waited for the camp (ref ID 5)

Beliefs about capabilities	Perceived competence	8	F (4), M (1), P (1), GP (2)	She used to squeeze her eyes…… roughly at the age of three years. We thought it's not normal so We searched for a hospital….Just for the normal eye check-up …. We went to the nearest eye specialist and We went in the same week. They could not detect the cataract. They just gave spectacle prescription. We doubted and went to other hospitals ….(ref ID 22) She had problem since beginning. She had trouble in seeing. She used to see like this bending her head on one side and squeeze her eyes always. Then we showed her some doctor. He did not say anything. He only gave number for spectacles. But her discomfort continued. After that we showed her to another doctor who gave medicines to eat. We did all this in our area, where we live. Our local doctor...It is within Delhi…Yes -yes, eye doctor. He checked and gave number... (ref ID 6)
	Perceived competence on government hospital	2	F (1), M (1)	We go to the government hospital, they say go to that place with this slip, or go to that doctor. And in our place if someone goes to the hospital, for one report nobody knows how many hours or days it will take. (ref ID 5)
	Optimism	1	P (1)	People said about Ayurveda [other form of medicine based on plants and herbs] treatment. We had tried with Ayurveda in parallel and came to know that by applying Ayurveda medicines in the eyes cataract could be cleared... (ref ID 18)

Nature of behaviour	Direct experience	6	F (3), M (2), WF (1)	We brought him once when he was even younger. He had cough. We were told that surgery cannot be done. So I thought, surgery cannot be done in very small children. (ref Id 13) In the government hospital only the doctor's consultation is free. You have to pay for the medicine. Then I went to the hospital. We visited four times. Then they did the surgery. The surgery was done for the nerves. We visited one month after the surgery for follow up. Even after surgery she can't see properly in the operated eye. (ref Id 30)
	Past behaviour	1	F (1)	Yes, there are these small capsules... We used to put those if there is redness or dust falls in the eyes. (ref Id 16)
	Routine habit	2	WF (28), F (1)	For weakness etc. we take medicine from the medical shops. If there is fever, we go to the nearby hospital. (ref Id 31)
	Breaking habit	1	F (1)	We always try to give healthy food to the children. But nowadays children also give trouble. They won't eat. If their mother cooks something, they might not eat. Some would ask for Maggi, some would ask for bread. (ref Id 6)

Knowledge	Knowledge about condition	19	F (9), M (5), P (4), WF (1)	Yes, I have heard about cataract before. Often older people get cataract surgery. So I knew about cataract. But, I never heard or saw cataract in children. (ref Id 10) Yes, I knew that cataract happens to older people. Didn't know that even our baby would have it. I used to notice white spots in both her eyes. I used to tell others in the house. They would say that it might happen to the child. It will be okay. (ref Id 10) We didn't know about cataract. Now see some people have brown eyes. We used to think that they have white eyes. We didn't know that they had cataract. We came to know about it later. (ref Id 20)
	Knowledge	5	F (4), P (1)	In the villages, many people don't know that children having eye problems should be taken to the hospital. There is no information. (ref Id 16)

5.4 Discussion

This mixed methods study is the first to explore the perceptions of parents' and carers' towards accessing childhood cataract services from multiple regions in India. This is also the first study to use TDF (which includes constructs from 33 behaviour change theories) in the field of community eye care to identify barriers and enablers for accessing childhood cataract services. This study has identified several barriers and enablers from the parents' perspectives and the three main domains associated with the enablers includes 1. 'Social influences', 2. 'Belief about consequences' and 3. 'Motivations and goals'. Similarly the potential barriers associated with the three main TDF domains include 1. 'Environmental context and resources', 2. 'Beliefs about consequences' and 3. 'Social influences' for accessing childhood cataract services.

A major concern reported by the parents and carers both in the quantitative survey and the in-depth interviews related to the financial and economic barriers to utilising the hospital services. These included: the hospital charges, transport, food and accommodation, and more importantly from the participant's perspectives the loss of wages when they are away to seek health care. Even when there is a possibility of free surgery at the hospital, the indirect costs associated with the treatment were reported to be a major barrier. Opportunity costs were a major issue as most of the parents had other family members including children and elders who depended on their income.

Previous research suggests that despite financial difficulties, health care utilisation is more likely if the illness is perceived to be either severe or life threatening (Russell, 1996). In the case of cataract, parents and carers in the community were generally aware of the development and management of cataracts in adults.

In developing countries, most of the adult cataracts tend to be treated late and once the cataract is mature (described as 'ripe' in local terminology). The post-operative visual outcome in these cases is generally good even with a mature cataract with poor pre-operative visual acuity (Venkatesh et al., 2005). In the present study, the elders in the family had significant involvement in decision making for health seeking behaviour. The elders' decisions are primarily based on their direct or indirect experience, and if they have not had experience of childhood cataract they may influence parents to delay surgery in children as it is considered as non-life threatening unlikely to have negative impact on vision.

However, economic issues did not deter parents from seeking surgery for their child if they were aware about the importance of early treatment and had access to a good health care facility. For example, parents with poor economic backgrounds expressed that, while they have no money available for this cataract treatment, they are keen to raise money from other sources as they considered vision to be important for the better future of their child. This indicates the importance of creating awareness towards early treatment in this population. For example, the families need to be educated about the risk of losing vision permanently in children with cataract if the surgery is delayed. Other factors influencing care seeking behaviour found in this study include proximity of the eye care facility, provision of free services and community screening programs closer to home.

Community eye screening program

One of the key findings from this study is that community eye screening programs in rural areas can act as both a barrier and an enabler for accessing cataract services in children. The qualitative interviews revealed that the parents were waiting for the community screening program to be organised in their vicinity to access free services for their children.

Community eye screening programmes are very common in rural areas as part of the National Program for prevention and control of Blindness (NPCB) initiatives in India (Verma et al., 2011) to improve service availability in rural areas (Natchiar et al., 1994). The purpose of these programmes is to provide screening in local communities, identify individuals with eye problems, and either refer them to the hospital or transport them for surgical treatment at no cost to the patients. This has been proven to be very successful in reducing blindness among adults caused by cataract (Murthy et al., 2005).

As discussed earlier in chapter 4 (page 162), school teachers undergo training as part of the school eye screening program and hence are able to identify cataract in children. In the current study, 10% of the cataracts were first identified by school teachers. Other than the school screening program, cataracts can be detected following general community eye screening that screen primarily adults. If any children with eye problems presented during the eye screening programme, the children would also be examined and if surgical intervention is required either given a referral slip or transported to the hospital by the screening team.

In most rural communities, parents generally wait for the screening programs to be organised in their local vicinity to seek free cataract treatment for their child. Though they may be aware of the problem and the need for early surgery, the inability to pay for the surgical services mean that they wait for the screening camp to arrive in the villages.
Although non-governmental hospitals provide free services, there is a limitation for the community to directly access these. The hospital internal system evaluates every parents' ability to pay for the services and gives them an indication of cost for the surgery. When the parents are informed of this cost they become concerned at their inability to pay, and in many cases this may delay the surgery. This needs more in depth study to understand ways of addressing this issue so that no parent waits for the screening program for their child's cataract surgery to avail free services to avoid resultant delay.

Another important finding from this study is that the referral slip provided during the community screening program inspires confidence and motivation to access hospitals in different towns as parents were informed about the hospital location and where they need to report. This helps parents from rural communities to access facility in bigger towns / cities or a facility located far away, since they may have difficulty when unaware of hospital procedures.

Beliefs about consequences

Although most carers accessed eye care centres after recognising the eye problem, a substantial minority chose to access traditional healers and other forms of care initially, potentially delaying the opportunities for optimal intervention. Previous research in developing countries about health seeking behaviour for childhood illness (Nasrin et al., 2013) has indicated that care seeking behaviour in resource poor settings is a hierarchical process, where carers first seek inexpensive solutions before visiting a hospital. Cultural beliefs based on religion and superstition were found to be an important impediment in accessing surgical services.

Social support

Another important factor that influenced access to childhood cataract services in this study was the social support provided by family and relatives and the wider community as a source of information and guidance. Cataract surgery in children is conducted after general anaesthesia and hence, it requires admission for a minimum of three days at the hospital and

mostly these hospitals are located in major towns and cities. This requires the family to travel out of their villages. The hospitals provide accommodation for one or two adults to stay with the child during the surgery. If the family has more than one child, the support system within the family becomes an important enabling factor for cataract surgery. Arrangement need to be made for a member (usually a grandparent) to look after the other siblings whilst the parents are away. Similarly, after surgery a support network is required to ensure good post-operative recovery in children.

Previous work suggests that any decisions regarding the child's health and access to care are made at the household level and that these decisions are largely influenced by household factors such as parents' educational and occupational exposures and mainly depend on the household income (Pillai et al., 2003). A similar pattern was observed in the present research. Also, parents in law played a major role in overall decision making in rural families and this is consistent with previous findings (Pokhrel and Sauerborn, 2004).

Champions of change in the community

In the villages, many champions of change for children's eye health have been identified by parents. For example, staff of government programmes such as Anganwadi (Nutrition centre) (Kaul, 1993) work closely with children and mothers and play a key role in creating awareness and linking the communities with the next level of care. Similarly, Accredited Social Health Activist (ASHA) (India, 2005) workers are engaged by the government of India under the National Rural Health Mission program to promote the health of rural communities with the support of ASHA workers for awareness creation and acting as a catalyst to promote utilisation of existing health care resources by the rural communities (Shrivastava and Shrivastava, 2012). One ASHA is appointed for every 1000 population and they too work very closely with mothers and children. They are provided with many educational materials and necessary training to identify and promote health and wellbeing within the villages.

Further important champions for change in the village were school teachers who were able to identify obvious eye defects and other major illnesses and play a major role in motivating the parent to take the child to the hospital (Limburg et al., 1995). In the current study, as previously discussed, around 10% of the cataracts in children were first identified by the school teacher.

It is important to note that the eye care professionals in rural areas and in smaller towns can give inappropriate advice to the parents about cataract surgery in children. This has inevitably caused delayed presentation for cataract surgery which is completely modifiable with continuous medical education programs to update the local practitioners' knowledge in rural areas as they play a crucial role in timely referral to tertiary centres for surgical services.

Although Knowledge was not identified as one of the top three domains in this research, it is important to note that most of the participants were not aware of the specific issues regarding childhood cataract. However, the prior experience of the family related to adult cataract may have had a greater influence in the parent's health-seeking behaviour. This finding contrasts with earlier studies, where knowledge among the parents about children's eye diseases was generally low but they were quite aware of cataract in children (Ebeigbe and Emedike, 2017, Senthilkumar et al., 2013a). This could be due to the majority of the respondents in this study being from rural locations, where eye care service availability is very limited, whereas both previous studies were based on urban populations.

Another important finding is that the beliefs towards squint in the community have not changed over the last 15 years. Similar to the earlier research findings (Nirmalan et al., 2003), in this research the participants expressed that strabismus ('crossed eye' or 'squint') has been considered as a sign of good luck in the family. Future health promotional programs should give specific focus on the issue of strabismus while developing health promotional materials for circulation in the community.

Strengths and weakness

This is the first study to look systematically at the barriers and enablers for childhood cataract services using the TDF to identify theoretical perspectives associated with the identified issues. The respondents included in this research were selected from 9 different geographical regions with broad cross-cultural representation. Also, the participants included parents, carers and other family members chosen from rural, urban and remote hilly and tribal areas to cover varied perspective on this topic. Another strength of this research was the researcher was born and raised in India, had worked in the field of rural and remote eye care for some years, and was thus able to communicate effectively with the data collectors at each hospital.

There are several limitations in this study. The in-depth interviews were conducted with the parents and carers who had already accessed the hospital for childhood cataract surgery. There would be many parents in the community whose children had cataract but had not accessed the services. The reported barriers and enablers from this study are therefore relevant to the members of the community who have accessed the services. Ideally, the barriers assessment should be focused at the community level from those who have not even touched the facility in the past for their children cataract needs.

Secondly, most of the interviews were conducted at the hospital premises, either at the time of admission for surgery or during the follow up care. The hospital environment may have had an influence, for example parents and carers may have felt obliged to give favourable answers thinking that their response would have an effect on their child's care.
Another important limitation in this study is the involvement of language interpreters to facilitate the discussion (Kapborga and Bertero, 2002). In some languages, the in-depth interviews were conducted with the support of local persons who had the language fluency to communicate with the participants in local dialects. This has an inherent disadvantage on the flow and continuity of the discussion as the questions posted by the investigator are translated to the participants in the local language and the participants' answers are back translated. It causes delay and can potentially impact on the interaction with the participants.

Barriers and enablers can act at the level of both provider of care as well as at the care recipient end. This part of study focused primarily on the receivers' perspectives and to lesser extent captured the perspectives of the providers. There are many different providers from the community to the advanced tertiary care engaged in eye care service delivery in children. However, in this research only the perspectives of the primary eye care providers' towards accessing childhood cataract services were collected and the details are discussed in the following chapter 6.

A deductive approach was used to code the data. All of the coded data were further analysed using an interpretive approach. An inductive approach would be appropriate in this context to identify new themes in the data, however no new themes emerged from these data, rather the data collected fitted well within the original TDF themes. However, the TDF domains did not fit the data perfectly in a few instances. For example, gender and religious beliefs were categorised under the domain Social Influence in this present study, but given the importance

of these two aspects the framework did not allow full exploration of the related issues. This categorisation may have limited the extent to which these issues were explored in the interviews and in the analysis.

Finally, cultural orientation to the community was an important factor to explore cultural issues practised within the community. Although this was an advantage for the researcher in this research, the cultural reflexivity of the researcher with preconceived ideas about the community and the concept of eye care delivery can act as disadvantage in certain situations mainly in critically interpreting the information and views from the community.

5.5 Conclusion

This study identified many barriers and enablers for accessing childhood cataract services from the perspective of parents' and carers'. Three TDF domains such as 'Social influences', 'Environmental context and resources' and 'Beliefs about consequences' were identified as having high importance and therefore are the theoretical domains most likely to be key mediators of delayed presentation for surgery. Several barriers identified in this research were considered modifiable and significant efforts are required to address at the community level.

Based on these identified domains a draft implementation plan will be developed to implement evidence-based changes in health seeking behaviour of the parents / carers and the details are discussed in Chapter 7. Our findings highlight that the TDF is considered as an useful approach providing a systematic, comprehensive, and theory-derived process to identify barriers to access childhood cataract services that can help identify target behaviours' for change and inform implementation strategies. Also, this study found that the TDF was a flexible approach that could be used across different settings and in different ways to understand planning and implementation of relevant activities.

Chapter 6

6 Knowledge and perspectives of primary eye care providers regarding childhood cataract services

Summary

This chapter focuses on the primary eye care providers' knowledge and perspectives regarding childhood cataract services in India. It starts with the introduction of primary eye care and its evolution and outlines the aims and methods of this study. The results section highlights current knowledge levels. Areas that require change and suggestions to improve the uptake of children eye care services at the community level are discussed.

6.1 Introduction

The concept of primary eye care (PEC) was born as a consequence of the Alma Ata meeting in 1978, with the focus to reduce two important causes of blindness in developing countries: (1) vitamin-A deficiency and (2) trachoma which could be addressed through the integration of primary health care services (Courtright et al., 2010). However, the concept of PEC started to expand, in terms of scope of work, when it was noted that a minimally trained health worker could probably diagnose a white cataract and recognise a red eye with minimal or no equipment (Sheffield, 1983).

Further development in blindness prevention programs across regions led to the inclusion of eye health promotion in the community to prevent conditions which cause blindness, and the recognition and treatment of common eye diseases. PEC services are supported by trained community-level health workers involved in the identification of children who need referral for ophthalmological assessment and treatment — such as any blind child or a child with a white pupil or corneal ulcer (Gilbert and Foster, 2001b). Although PEC has a component for children's eye care, most of the blindness prevention programs in developing countries have been targeted towards addressing certain highly prevalent eye diseases like cataract in adults (Dandona et al., 1998a) and more recently refractive errors.

There are a few successful models providing PEC activities focused on children. The most common one is school eye screening to identify and correct refractive errors. School based vision screening services are considered cost effective in detecting correctable causes of decreased vision (Limburg et al., 1995) and, as part of the National Program for Prevention and Control of Blindness (NPCB), school vision screening is widely practised at present in India (Jose and Sachdeva, 2009). Another model found to be successful in identifying blind children in the community with the support of trained local volunteers was the Key informant method (Muhit et al., 2007b).

As discussed earlier in chapter 1 (page 31) there is a need to raise awareness of children's eye care at the primary care level to recognise children with avoidable blindness conditions early and link them to the nearest facilities. In order to achieve this, the primary eye care team engaged in service delivery should be aware of all potential blinding conditions, their causes and treatment to effectively educate the communities, as they become the first contact point for the communities as an eye care service provider.

In this study, primary eye care providers fulfil a major role in the community in terms of raising awareness of eye health issues and encouraging families to access the cataract surgical services for their children. Their knowledge and awareness about cataract in children and their perception of barriers to uptake of care within the community is likely to impact their effectiveness in this role, and therefore the awareness and knowledge of families and their uptake of childhood cataract surgery services.

Currently, there is a paucity of qualitative enquiry into PEC providers' knowledge, experiences and views pertaining to improving the uptake of childhood cataract services in rural India. Hence, the exploration of barriers and facilitators for childhood cataract is important as a basis for programs intended to improve uptake of children's eye care services and to reduce blindness and visual impairment caused due to cataract. This study aimed to explore the factors that affect access to childhood cataract services among primary eye care practitioners in a rural, economically disadvantaged district in the state of Andhra Pradesh, India.

6.2 Methods

Study design:

A qualitative study was conducted using focus group discussions with rural PEC providers in the state of Andhra Pradesh to gain an understanding of the experiences, views and attitudes of these key stakeholders in order to inform the future directions of cataract services in children.

6.2.1 Study setting and participants

A purposive sampling method was used to select the study centres and participants for the study. Primary eye care providers include both Vision Technicians (VTs) and Community Eye Care workers (CECWs) (see Table 6.1 for a description of their training and roles). The participants were selected from the Prakasam district in the state of Andhra Pradesh, which has well-structured primary eye care services delivered by L V Prasad Eye Institute through its community eye care service. The district has 30 Vision Centres (VC) each with a CECW, who acts as a link between the community and the VC. Each VC is managed by a VT, a high school graduate with 1 year of basic training in optometry. The VT is usually identified from the local district and after training is usually posted in the same district. The VT works in tandem with the community eye care team, to develop horizontal linkages and identify opportunities to expand the reach and impact of primary level interventions (Rao et al., 2012). Each VC serves a population of 50,000 to 100,000 and 10 such centres are linked to a secondary centre for further treatment. Currently 3 secondary centres functions in the district which is further linked to a tertiary centre for advance level care in the neighbouring district.

The participants were selected from the staff registers maintained at each secondary centre with assistance from the respective hospital administrators. Out of three secondary centres, two centres were selected based on logistic convenience and a set of 20 VTs and 10 CECW were invited to participate in the discussion. The discussion was organised on monthly meeting day where the entire primary eye care team would be attending the secondary eye hospital for their review.

Table 6.1 Roles and responsibilities of Primary eye care workers

Category	Minimum qualification	Training duration	Service population	Key roles and responsibilities
Vision technician (VT)	Higher secondary school education and above	One year residential	50,000 – 100,000	• Responsible for managing an independent vision centre mostly in rural location. • Screening for eye diseases mostly at the Vision Centre, refraction, dispensing and referral services to the next level of care. • Community based screening, including schools and Anganwadi[10] centres and referring the children and adults with problems for treatment at higher centres. • Awareness creation in the villages
Community eye care worker (CECW)	High school and above	One month	10000 - 15000	• Door to door enumeration of households and identification of adults and children with eye problems • Facilitating referral linkage with the Vision Centre and higher centres • Organising community screening, school screening and Anganwadi screening programs along with the VT. • Awareness creation at the villages • Providing follow up services to the families for services uptake.

[10] Anganwadi centres are established for every 1000 population to provide nutritional support to pregnant and lactating mothers and children aged less than 3 years. This is part of government program implemented across the country.

6.2.2 Data collection procedure

Focus groups were conducted in the month of April 2016. Each focus group lasted approximately 75 minutes and was audio taped. Discussions were conducted in Telugu, (regional language) and the recordings were later transcribed in English for the analysis. The discussions were arranged in a separate room at the hospital. The lead researcher facilitated the entire discussion. The discussion started with the brief introduction of the participants and the facilitator presented an overview of the research program and focus group procedures. Also researcher encouraged everyone to participate and contribute to the discussion without any hesitation.

Data collection and tools

A semi- structured interview topic guide was used to guide each focus group discussion. The interview guide was developed based on the research questions prior to the data collection, on the existing literature and author's experience. The core topics for the focus group discussions with the primary eye care teams were to assess the following:

1. Knowledge of the PEC team and their attitude towards childhood cataract
    - How does cataract affect children?
    - Is cataract preventable in children? How?
    - When can a child can go for cataract surgery? At what age?
    - How often is follow up required post operatively? And for how long?
2. Barriers and enablers to access children eye care services by the community as perceived by PEC team
    - What are the perceived barriers for accessing childhood cataract services?
    - How can awareness of children eye care be created in the community?
    - Who are the catalysts in the community, who could potentially promote better eye health practices?
3. Challenges at the primary level to deliver children eye care services
    - Level of acceptance of PEC services by the community
    - Issues in convincing a parent / carer for increasing surgical uptake and referral services
    - PEC workers' perceived training needs
4. Perceptions towards gender, community practices and social influences on children eye health.

- What practices are followed in the community to treat eye conditions?
- Are gender differences apparent in seeking eye care?
- What family decision making dynamics are observed?

6.2.3 Data management and analysis

For the purpose of this research, conventional content analysis was performed in which coding categories were derived directly from the transcribed text (Hsieh and Shannon, 2005).

The data were extracted from all the transcripts and organized, using a deductive approach, by theme, in accordance with the objectives of this research. Using this method, sentences, phrases, paragraphs or lines were linked with codes; codes were then compared across the whole data set to identify variations, similarities, patterns and relationships.

Further, barriers and enablers to cataract services in children as perceived by the PEC team within the community were matched with the barriers and enablers reported by the parents and carers to identify similarities and variations in the perceptions.

Finally, the researcher looked for connections between and inter-relationships across themes to eventually construct a comprehensive narrative (Bradley et al., 2007). Further, all the identified themes were mapped with the TDF domains as this approach provides a robust theoretical basis for designing implementation to bring changes from the identified behaviour that needs change (Atkins et al., 2017).

Ethical consideration

A research participant information sheet describing the purpose of this research was given to the invited participants. Consent forms were signed by the participants before beginning the discussion. This study was approved by the School of Health Sciences, City, University of London and Institutional Review board of L V Prasad Eye Institute, in India.

6.3 Results

A total of 3 focus group discussions were conducted with 24 participants in total. The mean age of the participants was 24 years (range 20 – 32 years). VTs had worked in the Vision Centres between 1 and 36 months, and CHWs between 2 and 48 months. The demographic

profile of the participants is shown in Table 6.2. The average time taken for each focus group was 56 minutes (range 50 – 65 minutes).

Table 6.2 Demographic profile of the FGD participants

Variables	n (%)
Age	
20 -25 years	18 (75)
26 -32 years	6 (25)
Gender	
Male	15 (62.5)
Female	9 (37.5)
Job Category	
Vision technician (VT)	19 (79.2)
Community eye care worker (CECW)	5 (20.8)
Education	
School education	14 (58.4)
Diploma	3 (12.5)
Degree & above	7 (29.2)
Current work experience	
< 6 months	11 (45.8)
7 – 12 months	4 (16.7)
13 – 24 months	6 (25.0)
>24 months	3 (12.5)

Themes were generated separately for the knowledge and awareness of the PEC providers and PEC team's perception of barriers to uptake of eye care services within the community. The important themes identified and the example quotes from the discussion are shown below. Table 6.4 shows all the remaining quotes identified, grouped according to the theme and associated TDF domain. All the quotes generated from the focus groups are provided in Appendix 6.3.

Knowledge of Childhood cataract and its causes

Both VTs and CECWs were well aware of the major causes of cataract in children in these regions. Various causes reported by them include: consanguineous marriage in the family, maternal smoking and alcohol during pregnancy, poor maternal nutrition during pregnancy,

steroid use and eye injuries. However, although they had heard about 'rubella' they were not sure about how it affects children.

'Mostly, in many cases it [cataract] occurs because of consanguineous marriage. Otherwise, when the baby is in mother's womb, if mother had any health problem like diabetes, it may occur… I'm suspecting that it could be a possible reason' … (VT)

'Hereditary or it can cause through mother. If mother has smoking habits or drinks alcohol or she has thyroid, diabetes or BP problem it can affect her child with cataract'…(CECW)

In addition, VT's were aware of the importance of surgical treatment for unilateral cataract in children.

One eye has good vision and other eye has cataract, in children there is high possibility of amblyopia in cataract eye. Hence, I would give preference in referring a child with one eye cataract early to avoid amblyopia in that eye… (VT)

Knowledge on preventive aspects

VTs reported that cataract in children is preventable and were clearly aware of some preventive measures.

'In old people we can't prevent cataract, as the age increases it will definitely occur in individuals. But in children, we can prevent them if we avoid consanguineous marriage, blunt eye injuries and if the mother eats good nutritious food'… (VT)

When kids get injured they go and take drops from medical shops and apply. Which has more steroids drugs rather if they come directly to vision centres we can avoid to certain extent. In general, when eye injuries occur if we reduce the steroids use we can control this to certain extent. (VT)

Knowledge on age at surgery for childhood cataract

Surgery at an early age is important for effective treatment and mixed answers were reported by the participants related to this point. Some were clearly aware that the child can undergo surgery at any age as and others were not quite sure about it, especially the CEWs showed a lack of awareness on this element.

Surgery is based on age and the vision that the child has. In some cases it depends on the doctor who examines…some doctors advise it's not necessary to operate immediately ... ask them to wait for 3 or 6 months or come after one year...in such cases if the doctor advises to delay the surgery it's ok the child can wait for the operation. If the doctor didn't advise to wait all congenital cataracts need to be operated within one month from birth. (VT)

Don't know, may be at 15 years… (CECW)

Knowledge on post-operative follow up

Most of the VTs were aware of the importance of follow up after cataract surgery including patching to manage the amblyopia post operatively in children. However, the majority of CECWs were not aware about the follow up requirements and most of them reported information they gathered informally, rather than in training.

I'm not sure about how long the child needs to come for follow up after surgery. But their vision in both eyes will be different so they need to undergo patching and as per the doctor's advice the treatment has to continue after the surgery. After that every 3 or 6 months if they go for check-up it is good for the child... (VT)

I heard from someone after cataract *surgery follow up is recommended at 40 days and a check after 10 years is recommended... (CECW)*

I think for adults one month follow up is required but for children once a month for 6 months required after cataract surgery... (CECW)

Once a month for 6 months and after one year once to check their vision... (CECW)

Direct experience

Among the participants some reported that they had experience of seeing a child with cataract and most having encountered children with cataract during training at the tertiary hospitals, where the children attend for surgical services and post-operative follow up care. The personal experience of seeing a child with cataract either during the training program or at their respective centres helped them to know more about cataract in children.

'Last year when I was posted in tertiary hospital for my training, I saw a case… during holy festival his cousin had splashed/ thrown eggs on his face and it hit his eyes and developed cataract. So I realised, cataract can occur in children due to any eye injuries … (VT)'

A few participants reported that they have never seen a child with cataract so far in the villages and they were not aware earlier that cataract can occur in children.

'We have never seen a cataract in child in our neighbouring villages so far...but have seen a 7 year old boy with cataract at the hospital. He had cataract in both eyes and they advised surgery for both eyes. I was shocked to know that children at that age also get cataract... (CECW)

Perception about their training

The need for consistent and regular training was emphasised by participants. From the discussion, it was revealed that some have had the opportunity to see many cases of childhood cataract during the training while others saw none. The participants reported that there is a need to learn more about children eye diseases to deliver the service effectively in their areas.

No I haven't seen any during the training...during my training they said congenital cataract occurs in children mostly in families where consanguineous marriage happens...and surgery is the only treatment... (VT)

We didn't study about eye care earlier before coming to this job… We all started working in the community after training… but, we certainly need to know more on children eye care as it's not dealt with in detail during our training program… we need to know more about each conditions in children as the parents and communities expects us to answer their questions and also the knowledge on certain conditions will give us enough confidence to convince the parents… it will be good to have separate training sessions on children's eye disease to work effectively in the community…(CECW)

Perception towards children eye examination

Different answers were reported during the discussion related to the question on when the child should go for an eye examination irrespective of any eye problem. Many of them

expressed that the child has to go for an eye examination as early as possible from birth to identify any problems. However, some were unaware of when it is appropriate for the child to go for an eye examination and others had different answers indicating a lack of awareness among the VTs.

When the child is 6 or 7 years old. Because the child can't identify [letters] before that. Also when parents identify symptoms [such as] squeezing the eyes while reading and keeping the book closer to the eyes etc. Only when there is any complaint... Also when the child is 4 years old, the child can't express its eye problem hence 6 or 7 years is ideal. (VT)

'Yearly once eye check-up is sufficient for the child from the age of 3 onwards. (VT)

At 8 years it is easy to do refraction and identify the vision problems so it's good to examine a child around 8 years. (VT)

Home remedies for eye diseases in the community

It was evident from the VTs discussion that they were aware of harmful home remedies being practiced for treating eye conditions. However, community workers reported that the use of home remedies has decreased significantly in the communities and most of the villagers are seeking allopathic treatment for all conditions especially for eye care. But the major concern expressed in the discussion was about the use of over the counter medications for minor eye ailments causing more harm among the communities (Srinivasan et al., 1997).

'One time a 16 year old [complained of] *headache and at home they applied dry ginger juice near his eyes and he came to the vision centre with red eyes and his cornea was scarred and caused epithelial defects'…*(VT)

'Leaves extract for treating eye diseases is not there in the villages now. There is no person in the villages who practices such traditional medicines for eye problems. Generations have changed now so this kind of practice is not found these days'… (CECW)

'But what is quite common these days is that without going for eye check-up they buy medicines on their own from medical shop and apply. This practice is quite rampant in the villages now'… (CECW)

Perception toward families' decision making dynamics

Most of the participants reported that whether mother goes to work or not, she would be able to recognise any eye problem in the child and be able to make the decision to take the child to hospital. However, family dynamics practiced in rural areas are quite different (Pokhrel and Sauerborn, 2004) and understanding this phenomenon will be useful in designing awareness activities involving the decision makers. It was highlighted during the discussion that in educated families, either of the parents would make the decision about visiting the hospital depending on whoever is free, which is not similar in other rural families where *'grandparents' [are more involved] in such decisions. Mostly the parents are working in agricultural fields and the children are under the care of grandparents. So they observe the children so closely in such case they take the decision'. (VT)*

'Even if mother recognises the problem in the child she usually takes permission with her husband explaining the health condition of the child and takes the child to the hospital. They both will have decision about the child and take them to the hospital'. (VT)

Gender issues in the community

Most of the participants reported that there has been a significant reduction in gender discrimination, but it does exist in certain communities. The participants expressed the view that the reduced discrimination against female children is due to the state government program supporting girls at the time of their marriage. The participants expressed that in educated and rich families, they did not observe any gender difference in seeking health care. But in other families, they reported difference and it is interesting to note that for any eye surgeries girls will get more priority compared to boys and for general health care boys would get more priority compared to girls. It was reported that even in education there is a difference practised; boys going to private schools and girls to the government school.

In case of female child if any surgery is advised they go for surgery as soon as possible thinking it might cause some problem in future during her marriage time. So for eye surgery girls gets quicker treatment whereas boys surgeries gets delayed by the parents, if there are any concerns…(CECW)

Haven't seen any such discrimination…its equal nowadays in fact, girl's get more preference compared to boys these days. Because of the state government program (Bangara thalli) parents need not worry about dowry at the time of marriage… nowadays girls are treated better than boys…Even there is no difference in the way the health care is accessed or provided to the children. (VT)

'There are differences in education as boys are sent to private school and girls are placed in government schools. They are not allowed to go out [as much as] boys. But when it comes to health care there is no difference … very few families show the difference'. (VT)

Communication

Most of the participants reported that they need to use different means of communication to make parents and carers understand the importance of childhood cataract and to seek early treatment. It was highlighted during the discussion that the community gains confidence and trust in the team based on the way they communicate. They also reported that the team has to have patience to explain repeatedly to make the communities listen to their advice and to give lots of examples so that the disease and related issues are easily understood. The team expressed that the use of pictures, pamphlets and videos would facilitate communication in rural communities.

*Whoever accompanies the child either parents or grandparents we need to inform them about the surgery. If it is not operated, it will cause major problem. There are '**special doctors**' for operating in children... will motivate the parents and send them for surgery. (VT)*

It's very important to check whether they understood what we communicating... in villages the way they speak is different and we need to ensure... are we speaking in the language that they will be able to understand... (VT)

When we show some pamphlets with pictures they understand better, even if they can't read the text the pictures make them to understand what we communicate and make them think that even their problem may also be cured if they visit to the hospital… (CECW)

We always address them by uncle, aunty, grandpa and grand ma etc. so that they listen to us as if one of their family member is talking to them. We need to explain patiently and ensure they understood clearly…only then they will listen to us… (CECW)

Perception towards awareness creation

A lack of awareness among parents of children's eye disease was reported as a major barrier in accessing the services early and it was suggested that creating awareness through different communication modes will help in addressing child eye health issues in the community.

Participants said that village awareness meetings in targeted locations using stakeholders in the community and eye screening programs in schools and government nutrition centres could become useful and important activities for the dissemination of information about children's eye health services. Another important method for creating awareness in the rural areas suggested by most of the participants was using both television and social media to pass information about screening programs etc. Most villages have TV and a small advertisement highlighting the importance of eye check-up in children or about any problem may help to seek their attention quickly.

Other than this Anganwadi workers, Asha workers, nurses, vision technicians, government doctors, eye doctors and even veterinary doctors. Rural people take their cattle to the veterinary doctors. They can also create awareness about the eyes saying the eye problems can occur in cattle and as well as in humans even in children. So they can inform them to have eye check-ups… anyone in the public who has responsibility can create awareness. (VT)

It's better to organise awareness talks at government hospital. Because majority of the people from rural areas visit to government hospitals. Also it's good to keep pamphlets and display boards at the hospital. It is an opportunity to inform about the condition. We can involve nurses at Primary health centres to inform to the people. (VT)

Eye camps for children at the villages, school screening programs and door to door screening at the villages will be useful. Most children goes to Anganwadi centres and if we create

awareness among the mothers who visit Anganwadi centres they will recognise the problem early and take the child to the hospital… (CECW)

The group felt that awareness programs for pregnant women are important to raise awareness of all children's eye problems, especially childhood cataract. They believed that providing information to the mother about the need for an eye screening of the new born would increase the likelihood of screening either at the time of delivery at the hospital or during one of the immunisation schedules.

We need to target all the pregnant women, saying [whether delivery is early or late] *get your child's eye examined at an eye hospital …* (VT)

Perceived catalyst at the community

In the absence of a regular new-born eye screening program, early identification of cataract and other major eye problems in young children depends heavily on the parents and other catalysts in the community. The participants reported many stakeholders including village health nurses, ASHA workers, Anganwadi teachers, school teachers, church pastors and Panchayat leaders [11] in the community. Along with parents and family members these stakeholders have a common role in serving the welfare of the children in their community. It was suggested during the discussion that these individuals would be able to identify the eye problems in children early and educate the communities to increase the uptake of eye care services.

There are health workers at the village (Asha workers) and the person who gives immunisation at the village; they both can identify and inform the parents… Currently they are not doing it but they can do this task as they closely work with mother and children... (VT)

They respect the teachers as they are educated and they will have knowledge on these aspects so they listen to them… (CECW)

[11] Panchayat – an elected village council in India

They will listen to Family Relations and sometimes they listen to political leaders thinking that they may support financially for the service… (CECW)

Perceived barriers

Household factors, lack of awareness and distance to the hospital facility emerged as important barriers to uptake of children's eye care services. Household barriers revolved mainly around poverty in individual households which led to many individuals not having enough money to pay for transport to the nearest eye health facility. Long distances and travelling to bigger towns and cities for the first time with a young child were also reported as major problems.

First is money problem, next journey problem ...a few people stay in remote rural areas, for them long distance becomes a problem... Many doesn't know where exactly and which hospital to go... Those who live in rural area have no clues on how to go and locate the hospitals in the town... rural persons have problem in travelling to cities…. (VT)

Since most of the parents in rural communities are daily labourers (Jha, 1997), taking time off from work to visit hospital for a few days will result in a loss of wages, and this was reported as a critical factor in failing to seek early surgeries.

Parents in rural areas don't want to lose their daily wage and also they are not sure how much it would cost for the travel and treatment or they may not be aware of the place they need to visit… Because of all these problems they may not go to the hospital for treatment even though they are aware of the problem very well... (VT)

Challenges at work

The need for repeated home visits to persuade the community and to gain trust and confidence of the individual and the family has been reported as a major challenge involved in delivering primary eye care service. Most of the primary eye care team working in the field were young (*see table 6.2*) and it places them in a challenging role to convince the older and experienced parents and other community members.

A discrepancy was identified between the primary eye care teams' work and the community perception of their work.

If the family is educated they will listen to us immediately when we explain about the problem… they never look down on us and they appreciate our work…as we are going to their homes for their children welfare. But at the same time, some villagers are very stubborn, even if we explain as many times and make many visits, they are sometimes rude with us and say we don't need your help…sometimes they have said not to come to their home and literally forced us to leave their home…(CECW)

Since the primary care team provides the referral service to the tertiary centres, any problem with the surgical outcome of the referred case will have a negative effect on the primary eye care team.

Sometimes if the surgery had any issues they will come back and fight with us for giving referral... it's challenging to manage bad outcome cases at the primary level... (VT)

Another challenge experienced by the team is about the beliefs and perceptions among the communities. Some community members who are aware of hereditary conditions in their family link the child's eye condition to this and believe that nothing can be done.

Very few respond immediately after our advice and they go to the hospital and some ignore our advice and say we know about this condition and we will manage it. His grandfather had and his father also have cataract and now the child also has got it so nothing can be done… (CECW)

Similarly, considering squint as a sign of luck and therefore being reluctant to seek treatment are challenges faced in the community.

If it (squint) occurs in the right eye it's lucky for boys and if it occurs in the left eye it's lucky for girls. They also said that their grandfather and others in the family had it and it runs in the family and they think it won't cause any problem… (CECW)

Mapping themes with TDF domains

All the important themes identified from the discussions were mapped with the TDF domains and five domains which occurred a higher frequency were identified (Table 6.3).

Table 6.3 Themes from the focus group discussion mapped with the TDF domains related to knowledge of PEC team

Theme	TDF domain
Knowledge on preventive aspects	Knowledge
Knowledge on age at surgery for childhood cataract	Knowledge
Knowledge on post-operative follow up	Knowledge
Perception towards children eye examination	Knowledge
Home remedies for eye diseases in the community	Knowledge
Perception about their training	Skills
Direct experience	Beliefs about capabilities
Challenges at work	Beliefs about capabilities
Perception toward families' decision making dynamics	Social influences
Gender issues in the community	Social influences
Perceived catalyst at the community	Social influences
Communication	Environmental context and resources
Perception towards awareness creation	Environmental context and resources

Table 6.4 Themes from the focus group discussion mapped with the TDF domains related to barriers to uptake of services as perceived by the PEC team

Theme	TDF domain
Home remedies for eye diseases in the community	Knowledge
Perception toward families' decision making dynamics	Social influences
Gender issues in the community	Social influences
Perceived catalyst at the community	Social influences
Communication	Environmental context and resources
Perception towards awareness creation	Environmental context and resources
Perceived barriers	Environmental context and resources

Table 6.5 Themes and the quotations coded from the focus group discussion

TDF domain	Themes	Example excerpts from the discussion
Knowledge	Knowledge about childhood cataract and its causes	'When the mother consumed alcohol or smoked during pregnancy, there is a chance for the child to be born with cataract'. (VT) I learnt that the child gets cataract if the mother does not eat healthy food during the pregnancy... (VT) When the child's eye gets injured during the play... it can also lead to cataract…(VT) I heard that premature babies will also get cataract... (VT) If there was any issue during delivery it can affect the child. Also consanguineous marriage can affect the child…(CECW) Vitamin deficiency will also cause cataract in children they need to give vitamin A drops to the children otherwise it can affect the child with various eye problems…So mothers need to be counselled for giving children with more vitamin A rich foods to avoid problems…(CECW)
Skills	Personal experience of seeing a childhood cataract	Last year when I was posted in tertiary hospital for my training, I saw a case… during holy his cousin splashed/ thrown eggs on his face and it hit his eyes and developed cataract. So I realised cataract can come due to any eye injuries and electronic shock… (VT) Genetic problems can also cause cataract. I have seen more cases due to consanguineous marriage, there are a few cases in my own family itself.

		All got married within the relations and my cousin had congenital cataract and Retinitis Pigmentosa when I was young… (VT) I have seen a child at the community during a screening program... the child was around 3 years and from birth cataract was present... (VT) I have never seen in the community but have seen a 7 year old boy with cataract at the hospital. He had cataract in both eyes and they advised surgery for both eyes. I was shocked to know that children at that age also get cataract. (CECW) We haven't seen in villages but seen a few cases at the hospital during the training program. I have seen babies a few months old with cataract at the hospital. (CECW)
Knowledge	Knowledge on problems faced by children with cataract	Double vision, when they look at any object it will look double and when they look at the light it will look more colourful…no clarity and blurred image ….(VT) Cataract in young child affects growth and can lead to amblyopia as well… can cause retina problems also...as they have to strain more… I feel that their veins will lose its strength...because of that glaucoma can also occur… more chances for glaucoma…(VT) Children with cataract won't be active like others, as they can't see clearly and depending on others for everything…so they won't be very active…(VT)
Knowledge	Knowledge on prevention	If we stop consanguineous marriage we can prevent all cataract that occurs due to this... We should take care of the children from injuries… to prevent traumatic cataract…(VT) In old people we can't prevent cataract, as the age increases it will definitely occur in individuals. But in children we can prevent them if we avoid consanguineous marriage, blunt eye injuries and if the mother eats good nutritious food…(VT) When kids get injured they go and take drops from medical shops and apply. Which has more steroids drugs rather if they come directly to vision centres we can avoid to certain extent. In general when eye injuries occurs if we reduce the steroids use we can control this to certain extent. (VT)
Environmental context and resources	Home remedies used for treating eye problems	When a child had red eyes (conjunctivitis) they apply milk…either mother's milk or goat milk…Also when there is any dust fall in the eyes they said they used [sharp] pin to remove the dust from the eyes… When there is watering or white discharge in eyes… they mixed turmeric in water and applied on the eyes. All these cases have visited to my centre in this last one month... (VT) One time a 16 year old complaint having headache and at home they applied dry ginger juice near the eyes and he came to the vision centre

		with red eyes and his cornea was scarred and caused epithelial defects…(VT) In some old patients they come to the centre applying oil on their eyes and if we enquire they say they applied after prayers from the church thinking this will cure their eye problems…(VT) Especially very young children aged 2 months, 3 and 6 months babies, redness, watering and puss formation in the eyes are quite common. For such problems mostly they apply breast milk on the eyes of the babies. They believe that the breast milk will cure the problem…(VT) I haven't heard any traditional practice for eye problems, but have come across a few cases applying green leave extract on the eyes for fever and jaundice and lost vision and become blind. A 14 years old boy had this experience and become blind in our village, this happened 10 years ago…(CECW) Leaves extract for treating eye diseases is not there in the villages now. There is no person in the villages who practices such traditional medicines for eye problems. Generations have changed now so this kind of practice is not found in these days…(CECW) But what is quite common these days are without going for eye check-up they buy medicines on their own from medical shop and apply. This practice is quite rampant in the villages now…(CECW)
Skills	Perception about their training	Mostly it's learned during the work. Little information was given during the training about childhood cataract, mostly we gained knowledge when we started working at the vision centre. (VT) I have seen more cases during my practical postings in tertiary centre and also have learned at the vision centre (VT). No I haven't seen any during the training...during my training they said congenital cataract occurs in children mostly in families where consanguineous marriage happens...and surgery is the only treatment... (VT) We didn't study about eye care earlier before coming to this job… We all started working in the community after training… but, we certainly need to know more on children eye care as its not dealt in detail during our training program… we need to know more about each conditions in children as the parents and communities expects us to answer their questions and also the knowledge on certain conditions will give us enough confidence to convince the parents… it will be good to have separate training session on children eye disease to work effectively in the community…(CECW)
Knowledge	Perception towards	When the child is 6 or 7 years old. Because the child can't identify before that. Also when parents identify symptoms like when the child squeezing

	children eye examination	the eyes while reading and keeping the book closer to the eyes etc. Only when there is any complaint... Also when the child is 4 years old, the child can't express its eye problem hence 6 or 7 years is ideal. (VT) Generally immediately after birth the child is taken for check-up with general physician. It would be good to have the eyes examined at the same time and after every 6 months till the age of 8 years to treat amblyopia. (VT) At 6 years as it will be comfortable for vision test, the child will be able to understand and respond properly during the vision test. (VT) If we have to examine by birth every parents has to take their child to the eye hospital. In general, only they go to the hospital when there is any problem or when it is referred by the physician. The rural people have no awareness on eye check after birth. (VT) Children can't be express their eye problems hence if we screen the eyes of the child on yearly basis we can identify conditions early and treated... (VT) At 8 years it is easy to do refraction and identify the vision problems so it's good to examine a child around 8 years. (VT)
Knowledge	Possible eye conditions can be identified in very young children	Immediately after birth if we examine we can identify congenital cataract, glaucoma and even retinal problems. So it's better if they are examined immediately after birth. (VT) We can identify squint, retinoblastoma, cataract, glaucoma, micro cornea, bufophthalmos, big eye ball, corneal opacification etc. (VT)
Knowledge	Perception toward families' decision making dynamics	Mother, as she is responsible for looking after the child. She will be in a position to identify the problem but the decision to visit hospital is taken always by father. (VT) In villages, more than parents, grandparents' involvement is more in such decisions. Mostly the parents are working in agricultural fields and the children are under the care of grandparents. So they observe the children so closely in such case they take the decision. (VT) Always it's mothers' decision as the kids are closely monitored by the mother. Fathers always goes for work and they spend more time outside. Mother takes care of the child needs including food, medicine and all care… she the one who always identifies the problem… She also takes decision taking the child to the doctor. (VT)
Social influences	Gender issues at the community	Nowadays girls are given more care compared to the boys. More money is spent on boys these days. In my home, my sister is given the first priority compared to me. (VT) There are differences in education as boys are sent to private school and girls are placed in government schools. They are not allowed to go out

		compared to boys. But when it comes to health care there is no difference and very few families show the difference. (VT) In general the situation is better in villages in terms of treating both boys and girls equally. But still there are places where they treat differently…For example, in poor families the priority goes to the boys. Because they think boys will look after the family and hence they give more preference to boys' health and welfare. Girls will get married and go to other families but the boys will look after the parents so they treat boys better…In rich families both get equal treatment…(VT) Whether it's poor or rich family, the father becomes very happy when a boy born in the family as his family generation will continue through his son. Treatment will be same for both genders but the feeling of having son is different and they feel proud to have a son…(VT) There is no difference for seeking eye care between the genders. But there is some difference in seeking general health care in which girls gets delayed to treatment compared to boys…(CECW) In case of female child if any surgery is advised they go for surgery as soon as possible thinking it might cause some problem in future during her marriage time. So for eye surgery girls gets quicker treatment whereas boys would get postponed or delayed by the parents…(CECW) If the girl becomes blind the parents think it will not be possible to get her married in future whereas the boys get married even they become blind, so they go for treatment early for girl child…(CECW)
Beliefs about capabilities	How do you convince the parents / carers	Earlier surgery used to take long time now it just takes 5 minutes so not to worry. If you don't get operated vision will reduce and there is a chance to become blind as well. (VT) Whoever accompanies the child either parents or grandparents we need to inform them about the surgery. If it is not operated, it will cause major problem. There are '**special doctors**' for operating the children... will motivate the parents and send them for surgery. (VT) We need to clearly explain the good effects after surgery and the bad effects on the child's life if the surgery is not done on time... for the better life of the child the surgery is important and that need to be communicated clearly to them... (VT) It's very important to check whether they understood what we communicating... in villages the way they speak is different and we need to ensure... are we speaking in the language that they will be able to understand... (VT) You need to go for check-up for your child's welfare and life. If you ignore and delay it the child's life will get affected…(CECW)

		When we show some pamphlets with pictures they understand better, even if they can't read the text the pictures make them to understand what we communicate and make them think that even their problem may also be cured if they visit to the hospital…(CECW) They never listen at the first visit, we need to answer all their queries and explain everything in much more detail till they gain some confidence on us… it is important for us to communicate as if we are one of their family members… greeting them as sister / brother how are you? Such greetings makes them feel comfortable and it allows us to mingle with them…(CECW)
Emotions	Emotions	I won't explain about the surgery as they will get fear especially the child will get more fear and won't cooperate for surgery. So it's better to explain the parents when we refer the child for next level of service. (VT) Also I will explain the parents don't tease your child that he is not able to see properly... you are blind etc. some people scold the kids with such harsh words... because kids are so sensitive and it will hurt their feelings(VT).
Environmental context and resources	Perceived barriers	Money problem, transport problem and if they are labourers they say, if we go we will lose our daily wage and it will become problem and hence they delay the surgery.... when it becomes too much problematic they will go to the hospital for surgery... only some people delay it and others will go as soon as referral is given. (VT) Money problem and lack of awareness... not many are educated in rural areas and they not having clear idea about surgery and they have fear for surgery... (VT) If they not going for next level for treatment it could be possible that they didn't understand our explanation about the condition of the child. Or the place we referred may be at longer distance or they may not be able to leave their work and take the child to the hospital… Parents in rural areas don't want to lose their daily wage and also they are not sure how much it would cost for the travel and treatment or they may not aware of the place they need to visit… Because of all these problems they may not go to the hospital for treatment even though they aware of the problem very well... (VT) Children don't like to wear spectacles and moreover they break it often when the play either at school or outside. So parents sometimes thinks even if we spend so much money it goes waste as they don't like to wear or most of the times they break it. So many parents didn't like to spend money on spectacles. (VT)

		Instead of going to hospitals located in longer distance they try to show at somewhere near otherwise they just postpone it for a while…(VT) Parents don't have time to take the child to the hospital as they go for agricultural labour work. Also some have financial problems…(CECW)
Knowledge	Knowledge on post-operative follow up for childhood cataract	Some cataracts are treatable. If the cataract has occurred from birth in most cases it comes along with amblyopia. In such cases vision will not improve just with surgery. They need patching after surgery and regular check-up and treatment on monthly basis. (VT) I'm not sure about how long the child need to come for follow up after surgery. But their vision on both eyes will be different they need to undergo patching and as per the doctor advice the treatment has to continue after the surgery. After that every 3 or 6 months once if they go for check-up it is good for the child... (VT) I don't know how long the follow up will be required for a child after cataract surgery…(VT) I think the follow up would be much longer as they are kids… and there is a chance for injury after surgery and we are not sure about the IOL implantation status so I think the follow up would be much longer... (VT) After surgery within one week first follow up will be organised and after that every 3 months or every 6 months the follow up will be required depending on the child's eye condition. (VT) After surgery the first follow up within one week and again at one month and afterwards every 3 or 6 months till they reach 20 years. The maximum growth will be achieved by 20 years and for any children eye problems the maximum follow up period is 20 years. (VT) One month follow up is required I think, afterwards I'm not aware...(CECW) I heard from someone after cataract surgery follow up is recommended at 40 days and a check after 10 years is recommended...(CECW) I think for adults one month follow up is required but for children once a month for 6 months required after cataract surgery...(CECW)
Knowledge	Knowledge on age at surgery for childhood cataract	If cataract occurs in a child it needs to be operated before 8 years because after 8 years the child will develop amblyopia. (VT) There is no such time limit. I feel depending on their convenience if they can go early is better, that's my opinion. (VT) If it is one month baby it will not cooperate. It may rub the eyes and the parents will feel fear to operate. I have seen very young kids getting operated but we need to explain the parents and get the child operated within one year. (VT) No idea… on what is the correct age for undergoing cataract surgery in children…(VT)

		After 21 days from birth the child can undergo surgery… as many in the village won't take their child outside for 21 days other than for any emergency reasons…(VT) Don't know, may be at 15 years…(CECW) Even one year child can go for surgery. I have seen very young children undergone cataract surgery at tertiary centre…(CECW) Age has nothing to do it all depends upon the cataract. If the cataract is in operable stage, surgery can be done immediately and if the cataract is not in operable stage they can wait for some more time as per the advice of the doctor. It's our thinking but not very sure…(CECW)
Environmental context and resources	Perception towards awareness creation	Awareness creation is must... Government or private organisations can do… TV ads can be good…highlighting cataract can occur in children and if not operated they can go blind and early surgery is important to treat the problem such ads can be given either by government or private organisation. (VT) Nowadays most of the villagers' economic status is better and many are visiting private hospitals in towns and cities. If we can meet with those private doctors and introduce ourselves from eye hospital, especially at delivery homes and inform them to arrange for check-ups after delivery and ask them to inform the parents. Through this methods and through pamphlets and advertisement, if we do all these people go to hospital early. (VT) Everyone says different method, but I feel if we show videos to create awareness it will be much better. (VT) It costs lot of money for all media awareness. Instead we involve friends group at the village they can go and inform everyone at the village. Also we can contact panchayat and through them we can inform everyone. Many does this way...if we contact the panchayat they will do it at free of cost...community will think about panchayat president doing some good work for the community. Also through friends group we can inform the rural masses about eye care… (VT) It is important to follow up with the family to check whether they went to the hospital for the treatment and them adhering all the advice given... we need to counsel one to one step wise in detail for them to understand the issues clearly… (VT) School screening has to be done. Also awareness talk or skit for 10 minutes on children eye diseases should be displayed in all local TVs. When parents see such ads on TVs they will associate with their child behaviour and take the child to the hospital…(VT)

		Eye camps for children at the villages, school screening program and door to door screening at the villages will be useful. Most children goes to Anganwadi centres and if we create awareness among the mothers who visits Anganwadi centres they will recognise the problem early and take the child to the hospital…(CECW) Many parents in the villages do not recognise vision problems in children till they grow older. Only when the child unable to take whatever is given by the parents they start realising there is some problem in vision of their baby… so children eye screening is required… (CECW) At every village, village health nurse (VHN) maintains the list of new born babies for immunisation purpose. The hospital community workers can get the list from the nurse and visit door to door as per the list and we can recognise the problem early and refer it to the nearest vision centre to confirm the cases. Even if the worker has slight doubt she can refer the child to vision centre to confirm… (CECW) There are a few examples in villages, even kids realise that they can't see properly they fear to say that to the teachers thinking that they will beat them for complaining and also for same reasons they won't share it with the parents and have lost vision. … (CECW)
Beliefs about capabilities	Challenges at work	We explain very patiently to most of them but only 75% of them listens to us and 25%never listens to anything...they think who these young people advising to us...in such situation if we play video recordings...they will watch that and there is no need to explain. By looking at the video they will themselves come forward and ask for details if necessary. It will be easy as well as there won't be any necessity to explain individually. (VT) Not many go to the hospital even after referral. They don't take it serious and they believe nothing will happen as the child grows older the problem will get resolve on its own… Thinking this way they won't go to the hospital for immediate check-up…(CECW) They never listen to us in the beginning, at least we need to make three to four visits to make them listen to us. Even after number of visits if they don't listen then we usually identify another person who had received treatment from the hospital and request them to convince this person who is not willing to undergo treatment…(CECW)
Social influences	Catalyst at the community	Anganwadi nutrition centre workers they closely monitor the under 5 years children and they will be able to recognise the problem…(VT) Compared to all these health workers the person who spends more time with the children at home can recognise the eye problem easily based on the behaviour of the child and some symptoms like…not looking directly, when the eye lids are not closing properly etc.…So the person who spends

		more time with the child can recognise problems in children others can't recognise early. (VT) School teachers can identify based on how the child behaves in the school and inform the parents to take the child to the hospital. In some families kids are looked after by grandparents and sometimes they may not be able to recognise eye problems …also some parents don't care much about their children in such cases school teachers have major role in recognising the problem…(VT) In some families they don't even listen to their relatives in certain situation. For e.g. if the child has to go to a hostel facility for better education they won't listen to any one but if school teachers or church pastor speaks to them about the importance of education they will listen to them…(CECW) If we know that they particularly listen to some one in the family either it could be uncle or grandfather we need to discuss with them to convince the parents…(CECW)
Beliefs and consequences	Perception of the communities about squint	They consider squint as lucky especially in girl child. They don't go for treatment for squint…(CECW) Some believe squinted girl will get married to good husband in future…(CECW) Most of them feel it's lucky and they don't aware that there is a problem in the eyes and it could be treatable…(CECW) Some educated parents aware about this issue and they are taking the child with squint to various hospitals for seeking treatment…(CECW)

6.4 Discussion

In this qualitative study from a rural Indian district, key barriers and enablers for increasing the uptake of children's eye care services were identified from the perspectives of primary eye care providers along with the TDF domains associated with them. Participants reported inadequate experience in childhood cataract, with nearly two thirds of the participants having less than one year of experience working in the primary care setting. The majority had not seen a cataract case in the hospital during their training or in their community work. This suggests a lack of standardisation in the curriculum for training the primary eye care team in childhood cataract. A standard curriculum does exist for VTs including cataract, but adult blindness is prioritised as discussed earlier (Dandona et al., 1998a). Hence, development of new training materials on childhood blindness, particularly for primary eye-care and secondary eye-care workers is important and this has been emphasised in other studies as well to address this issue effectively in the future (Gogate et al., 2009).

Given the complexity and varied nature of eye and vision disorders in children, preventing blindness in children is one of the priority areas for VISION 2020 (Thylefors, 1998a) and one way to achieve this is to ensure primary eye care activities targeted towards children are strengthened. Since eye care provision tends to focus more heavily on adults than children, one possible solution may be to have a separate cadre of community eye health workers specifically trained to identify, refer and provide follow up services for all eye care needs in children for every 50000 population and above, including approximately 15,000 children.

Any success in blindness prevention programmes is associated with the level of awareness of eye diseases, their prevention and treatment among community and eye care providers (Hubley and Gilbert, 2006). In the present study, the primary eye care team perceived or demonstrated significant gaps in knowledge about childhood cataract among the rural communities. This lack of knowledge needs to be addressed in future childhood eye care programs. Similar findings were derived from the qualitative interviews with the parents and carers discussed in the previous chapter. The eye care provider respondents indicated that the use of mass media including television advertising and videos in health centre waiting areas would be very useful in creating awareness about eye conditions. The potential of this method has been tested previously in India and found to be cost-effective in promoting eye health (Murthy et al., 2001).

Community eye health workers reported that the use of home remedies have reduced in the villages. However, despite the reduced use of traditional medicines, the present research findings indicate that some cases of adverse reactions to such remedies are still seen at the primary eye care centres. Traditional treatment and cultural beliefs are considered as an ongoing challenge in developing countries (Gilbert, 2007) and this issue requires prioritisation while developing eye health promotion strategies .

The participating eye care providers suggested that eye health should be promoted within schools, with the intention of raising awareness among children of signs and symptoms that may allow early identification of issues such as childhood cataract. Previous work among school children indicates that models of this kind are effective, (Webb, 1988), however, this strategy should be tested in this population as part of the proposed plan to improve health seeking behaviour among the communities.

Prevailing inequalities in eye care provision between urban and rural areas remain an issue in India. Vision centres are established in rural areas to bridge the existing inequalities in eye care and to create an accessible, affordable quality eye care available close to the rural population (Kovai et al., 2012). However, there are challenges within the community to accept the services offered at the centre. Continuous guidance and supervision may be useful for the rural primary eye care team, including some with little experience or training, to gain more confidence in the delivery of eye care services. Also, providing knowledge and awareness about the range of eye conditions through a continuing education program might be very useful in developing the PEC teams' confidence and ability in communication with parents and carers, an issue which has been found to be a contributing factor for service continuity among the communities (Rodriguez et al., 2007).

As discussed in chapter 5, the TDF domain 'Social influences' was identified as one of the major domains associated with barriers and enablers for accessing cataract services in children from the perspectives of the parents and carers. Similarly, from the perspectives of the PEC team this domain has an important role in influencing health seeking behaviour. For example, gender differences continue to be an issue in health seeking in this population not specific to cataract in children,(Iyer et al., 2007) despite government programs to promote the welfare of girls in the state (http://gcps.ap.nic.in/). Though it was perceived that the

situation has improved over time, from the perspective of the PEC team in this research some gender differences still exist, such as the education of girls in government school compared to private school for boys, and more rapidly seeking treatment for boys when they are ill compared to girls. Similar findings were reported earlier particularly in uneducated poor families (Iyer et al., 2007).

Most children's health awareness programs are targeted at mothers, since mothers play a central role in providing care for their children. However, in many families, the father or in-laws will be the decision makers who decide when to visit the hospital to seek treatment (Pokhrel and Sauerborn, 2004). Consistent with this, in the present research it was perceived that mothers are not always in a position to make an independent decision on utilising the hospital services for her child. Awareness programs or one to one counselling to increase the uptake for eye care services should involve the decision makers in the family for desirable change in the community.

Economic factors and longer distances to eye care facilities were perceived by the rural PEC team as two major barriers to the utilisation of eye care services. Cataract surgery in children requires a stay at the hospital and a number of follow up visits after surgery. This requires care providers to take time away from work and pay for transport, making this challenging for the families, particularly those on low incomes (Gilbert and Muhit, 2012a). This factor aligns with the TDF domain 'Environmental context and resources' and this was identified as a major barrier across different studies.

Vision 2020 recommends the establishment of one paediatric eye care facility per 10 million population to provide comprehensive eye care for children in need (WHO, 2002, WHO, 1997). In many developing countries including India, most of the paediatric eye care facilities are based in larger cities, causing rural residents to travel long distances for eye surgery in children and for repeated follow-up appointments. Hence, the role of the primary eye care team becomes very important in bridging the communities with the available surgical facilities for the eye care needs of the children. Awareness of the importance of treatment and follow up care is essential to guide and motivate parents and increase the uptake of these services in children.

The need for standardised training of the primary eye care team focused on children's eye health services was a recurring theme across the respondents. This highlights the need to address knowledge gaps among the primary eye care team in order to improve screening, identification, counselling, referral and follow-up services for children's eye health needs. Respondents raised the need to consider and address challenges related to the cost involved in travelling to cities to access surgical services for the children. The point that poverty limits access to children's eye health services should be considered in the design of blindness prevention programs aimed at children in rural, low income settings.

Limitations

A limitation of this study is that participants included eye care providers from only one district in one state. Focus group discussions in multiple districts covering different states would add more value in this topic as there are differences across the country in the availability of primary eye care teams and their training programs. Hence, the findings of this study need to be interpreted cautiously and therefore transferability to a larger population might be limited. For example, in the region on which this study focused, some eye care services are provided free or at highly subsidised rates, which may not be true for most other parts of rural India. However, the respondents identified some factors that can be addressed in the future to improve the uptake of children's eye care services and which are likely to apply more widely.

Finally, though the translation was conducted verbatim to include all words and pauses, it is possible that some of the meaning of respondents' experiences, particularly the expressions of the participants during the discussion and perspectives may have been distorted in the process of translating the transcripts from the local language into English,

6.5 Conclusion

The present findings indicate that there are significant gaps in knowledge about childhood cataract among the primary eye care team and a lack of awareness among rural communities about children's eye problems and the importance of early intervention, at least as perceived by the PEC team included here. As the PEC team works as the first contact point within the communities, the knowledge gaps within the team have to be considered crucial and given priority during the proposed implementation. Also, the suggestions made by the PEC team can form the basis of development of improved eye care promotional activities in the region and are likely to apply to other regions in India. The themes identified were aligned with the

domains identified by the parents and carers as described in the previous chapter. The TDF domains and the themes identified through the parents and the PEC team can be used to develop theory-informed interventions for bringing positive behavioural change in the communities.

7 Summary and conclusions

Childhood cataract is an avoidable cause of visual impairment and blindness in children and has been identified globally as one of the important priorities under the VISION 2020 initiative: Right to Sight to reduce blindness in children. This is more important in developing countries where the problem of blindness and visual impairment is particularly severe. With a relatively low prevalence of childhood cataract of around 1.2 per 10,000 children it is quite challenging to establish programs at the community level, since more prevalent issues may take priority. However, it is important to understand that most cases of cataract in children are treatable provided they are identified and managed at an early age.

In the recent past, India has made great progress in battling blindness in adults and as described in Chapter 1, recent surveys show that the overall prevalence of blindness has reduced in the country. Volumes of published materials related to successful blindness prevention models in adults and the progress made so far is well documented in India and the efforts are continuing in this area to make further progress. By contrast, there is a paucity of research on the burden of childhood cataract, systems for screening and recognition, the age at presentation for surgery and especially the barriers and enablers to access cataract services in children from the perspectives of the parents and carers in India. Only two retrospective studies have focused on delays to childhood cataract surgery in India and the details are discussed in Chapter 1, under the section on delayed presentation for childhood cataract.

In order to make eye care services available, accessible and affordable for children across the country, research must be undertaken that builds upon the limited empirical base currently available in the field of childhood cataract services in India. Specifically, the knowledge base must expand to include determining the age at cataract surgery in children in different geographical regions and the existing barriers and enablers for accessing the services both from the perspectives of parents / carers and the primary eye care providers in the community who act as the first contact point for the community.

The present study employed a mixed methods approach combined with systematic review methodology to estimate the prevalence of childhood cataract and used quantitative and qualitative methods to identify barriers and enablers associated with uptake of childhood cataract services.

In order to develop and evaluate interventions to improve cataract surgery outcomes in children, it is important to understand the factors associated with the late presentation for surgery.

There is overwhelming evidence that behaviour and behaviour change play an important role in people's health and health-related actions and there is evidence that interventions to improve outcomes are likely to be more effective if they target the specific issues associated with the health-related behaviour. To identify these issues the theoretical domains framework (TDF) was used which comprised 12 theoretical constructs of behaviour change. TDF provides an accessible, conceptual basis for understanding barriers and enablers of behaviour change, exploring implementation problems, designing implementation interventions to improve health care practice, and furthering our understanding of the processes of behaviour change.

The ensuing pages of this report discuss the investigation in three parts: first, a summary of study and results; second, a positing of the implications of those results; and third, a proposal of three kinds of recommendations—(a) for further research, and (b) for the practitioners and participating hospitals in this research (c) future directions in policy making.

7.1 Summary of Findings

Results for research aim # 1

The systematic review conducted as part of this research on the global burden of childhood cataract estimated the overall prevalence of childhood cataract and congenital cataract ranged from 0.32 to 22.9 per 10000 children (median =1.03) and 0.63 to 9.74 per 10000 (median = 1.71), respectively (Table 3.9).

The findings suggest that there are substantial gaps in the epidemiological data on childhood cataract worldwide. While prevalence data from high income and upper middle income economies are consistent, very little is known on prevalence, and nothing on incidence, from low and lower middle income economies where evidence points to high prevalence of childhood blindness (Figure 3.6). This review raised two important issues to be considered in further research. The first of these is a lack of clarity in defining cataract in children

(congenital vs developmental). Secondly, most included studies estimated cataract based on visual impairment rather than the degree of lens opacity, and this had significant implications on estimating the burden.

Although it is a very conservative estimate, the estimated number of children with childhood cataract in India ranges from 32481 to 82956 and no data on the number of children new cases each year. This number appears low when compared to the common occurrence of cataract in adults at all locations, it becomes a significant problem when we calculate the number of years these children are expected to live with low vision. Also, the blindness and visual impairment caused due to cataract can be avoided in these children if they receive all necessary care at the appropriate time.

Results for research aim # 2

The second research aim focused on the age at which cataract surgery is conducted in children to estimate the delay for childhood cataract surgery. The findings are consistent with previous retrospective research reports which highlight significant delays in accessing the childhood cataract services in India. The findings from the present study demonstrate that the mean age at surgery in India is estimated around 4 years for congenital cataract and 8 years for developmental cataract (Table 4.3). Despite two thirds of cataract cases in children being recognised within one year from birth, only half of them completed surgery before reaching one year of age (Figure 4.8). Also, the mean age varied significantly between the regions in India. Compared to South and Western regions, the mean age was 2 times higher in Central and 2.5 times higher in North and Eastern regions in the country suggesting different approaches are required to address this delay in different regions (Figure 4.9). Utilization of cataract surgical services across all regions was lower among girls compared to boys, although there is no difference in the prevalence rates in the literature, however, there was no statistical significance for this association. Another important finding is that parents / carers, other family members and school teachers played a major role in recognising cataract in children.

Results for research aim # 3

The third research aim was related to understanding the barriers and enablers associated with childhood cataract services. The findings suggest that there are delays at three stages

including: recognition, access to hospital cataract services after recognition and delayed surgery after it was advised at the hospital.
Using the TDF, the factors affecting delay to services from the perspective of parents and carers can be categorised as (1) Environmental context and resources (2) Beliefs about consequences and (3) Social influences. The second and third domains included barriers but also some enablers, which were also aligned with the domain 'Motivation and goals'.
Within the first domain (environmental context and resources) barriers included economic factors such as the loss of wages and transport costs incurred due to hospital visits, exacerbated by a lack of local services and thus a need to travel long distances.

The domain 'Beliefs about consequences' includes parents' beliefs about traditional practices, their attitudes towards preventive eye care for children and giving low priority to the eye complaint reported by their children. However, these factors also suggest some important themes that could enable the parents and carers to access surgical services earlier for their child. Enablers in this domain include awareness of the importance of eye sight in the child's life and reinforcement given by doctors on the importance of early surgery.

Similarly, the domain 'Social influences' included both barriers and enablers. Barriers include the social norms and cultural practices adopted in the community and the lack of social support which act as a hindrance to accessing services. Conversely, social support either from the family or community members available at the time of decision making or to take the child to the hospital was also identified as an important enabler. The influence of change agents at the community has been reported as an enabling factor for accessing surgical services.

Another domain which included enabling factors was Motivation, goals and intentions. When the parents and carers were keen to seek eye care services for their children, they were willing to go to any lengths to access the services for their child. Also, when they saw their child benefiting from the surgery, they were motivated to help others in promoting the importance of surgery and eye examination in children in their respective communities.

Results for research aim # 4

The fourth research aim was related to knowledge and perceptions of primary eye care providers regarding childhood cataract services. The knowledge levels among the vision

technicians (VTs) and the community eye care workers (CECW) about childhood cataract services were quite high in some aspects of childhood cataract. For example, knowledge on the causes of cataract in children was relatively high while knowledge of the age at which the child can undergo cataract surgery was varied among respondents. Knowledge levels were different among the team who had experience of more than one year at the community level compared to newer and less experienced team members.

However, it was clearly stated that the exposure given during their training program before their clinical placement at the primary eye care centres was different between the training cohorts, with only a few team members having had the opportunity to see children with cataract during the training programs.
Knowledge of post-operative follow up after cataract surgery in children was also varied. The team members' existing knowledge was based on information gathered from different sources rather than during formal training.

The PEC teams were aware of the level of parental knowledge of existing traditional practices and decision-making dynamics in the community. They used this knowledge to plan communication strategies in their work to convince parents and others of the importance of accessing surgical services. The team perceived that the lack of parental awareness about the eye problems, distance to the hospital facility and economic reasons prevented the community from utilising the available services. The team also expressed the need to create more awareness in the community about children's eye care services and listed various catalysts such as Village Health Nurses, ASHA workers, government nutrition centre teachers, school teachers, church pastors and panchayat leaders[12], who would be able to influence the local communities, change their perceptions and thus increase the uptake of eye care services.

7.2 Conclusions and Implications

The findings arising from the systematic review of the global prevalence and incidence of childhood cataract indicate that there is a need for more population based estimates of the burden of childhood cataract from developing countries which can form a basis for future

[12] Panchayat – an elected village council in India

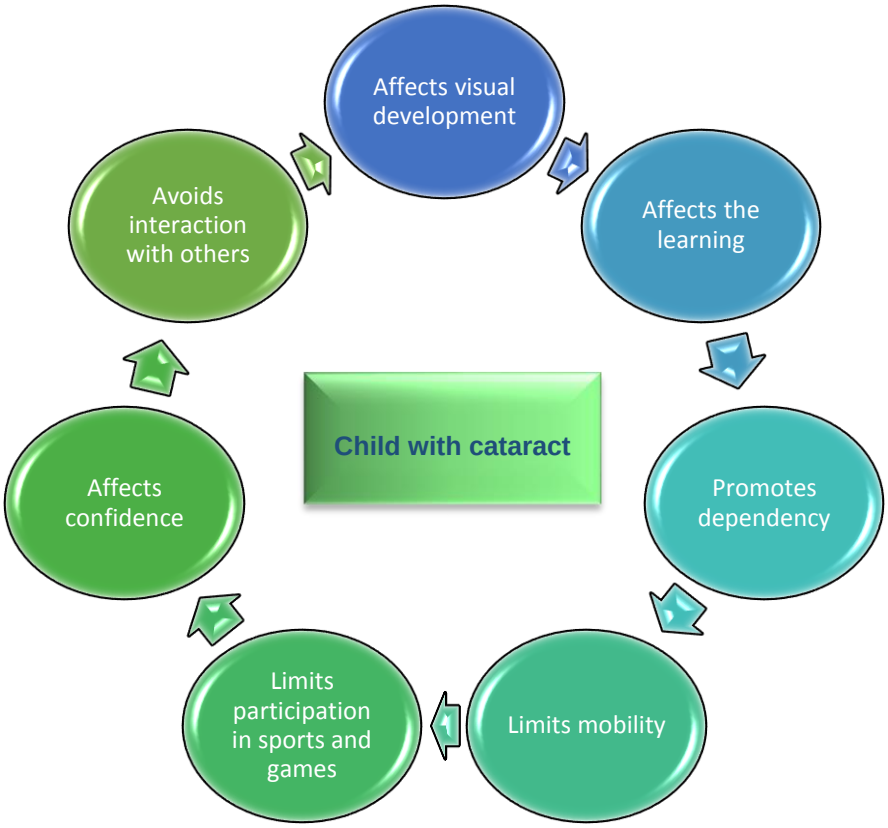
policy decisions. The blindness prevention activities in developing countries are facilitated by the government policies and to prioritize childhood cataract prevention initiatives at the national level requires more evidence on the burden including both prevalence and incidence of childhood cataract from different regions.

The number of children with childhood cataract may appear small due to the low prevalence of cataract in the whole population, but it has profound implications for the individual child, family and for the community at large. The cataract in children can have a significant impact on the quality of life of the child due to the number of blind or visually impaired years that the child will be expected to live.

The untreated visual disability caused by cataract affects the overall personal and educational development of the child during the formative years of the child's life (Figure 7.1). In the case of congenital cataract the child has to go through many challenges including compromised early visual development and high dependency on the family. In children who develop cataract during their school years, the condition is likely to affect their educational and outdoor school activities to an extent, depending on density of the cataract and whether unilateral or bilateral. The child may also face social isolation due to this visual disability.

Delayed presentation for childhood cataract surgery was identified as a major problem across the country. Although the recommended period for cataract surgery in children as early as possible as discussed in Chapter 1, (section 1.4: cataract surgery in children), in this study, only half of the children underwent surgery within one year of age and in the remaining cases the surgery was delayed between 2 to 10 years. As discussed in section 1.4.2 in Chapter 1, delayed childhood cataract surgery has implications for the visual outcome and these children require low vision services to use their residual vision. However, the availability of low vision services is very limited making it much more challenging for the children to gain their full potential. In addition to delays in accessing surgical services, every child that undergoes cataract surgery needs to have continuous follow-up post-surgery in order to achieve an optimal outcome.

Figure 7.1 Challenges faced by children with cataract



As described in Chapter 1, blindness in children is associated with infant mortality in developing countries, making treatment of cataract particularly important in cases causing blindness.

Though there was no statistical significance achieved, but the finding that relatively few girls in India access cataract surgical services has several implications for the gender neutral policies of the Indian government. No clear reason was found for this gender difference, but it is likely to be related to the existing attitudes towards gender and the differences in accessing surgical services as described in chapter 4, in the discussion section. However, this is important to be explored and addressed in future research in these regions.

If a child suffers with cataract, members of the family have the potential to facilitate early treatment by recognition of the cataract, realising the importance of the surgery, identifying the hospital, finding time, money and resources to access the services. Given the low education level of parents in rural areas and a lack of awareness about childhood cataract,

late recognition by families is common. Moreover, in most families either one adult member or the eldest sibling is expected to dedicate their time to looking after this child. If an adult member, this is likely to reduce the family's income, and if it is a sibling she or he has to sacrifice their education.

Secondly, cataract treatment in children requires ongoing treatment and follow up to ensure the best possible outcome. Hence, the family has to make a number of visits to the hospital, which usually involves travelling long distances, taking time off from work with a loss of pay, arranging someone to look after other dependents in the family, cost of accommodation and food. All these factors might cause an additional economic burden in these families and they were reported as the main barriers for accessing cataract services in children in this population.

Finally, it seems likely that due to the child's eye condition, the priorities of the families may be shifted around this child with some resulting level of neglect of other children within the family, including care, attention and social activities. Alternatively, perhaps the family may neglect the needs of the child with cataract and focus on the rest of the family's needs.

The community includes the extended society, hospitals both government and non-governmental organizations and the policy makers. Cataract in children has many implications for the existing health systems. Treating or avoiding blindness and visual impairment in children requires policies that address treatable disease conditions including cataract. Policy decisions have implications for the development of adequate infrastructure to facilitate early recognition and access to treatment, including trained ophthalmic personnel and the necessary equipment. However, this requires a significant financial commitment from the government and to date the NGO hospitals have had a significant role in addressing this issue.

The quantitative results from the present research highlight not only delayed presentation for treatment of childhood cataract but also a significant variation in this delay within the country. In order to avoid cataract-associated blindness and severe visual impairment in children, a regionally specific targeted approach is required to understand the issues at various level to minimise the delay in accessing cataract surgical services.

The barriers and enablers from the parents' perspectives indicate that there are some key issues causing delay in accessing childhood cataract services. These issues require behavioural change interventions at the community level based on targeted behaviour' identified for change in this research using the TDF approach.

Similar to barriers and enablers from the perspectives of the parents, the primary eye care providers' perception points to a need to address a lack of awareness among the rural communities of the importance of early intervention. This research also shows that there are existing knowledge gaps about childhood cataract among the PEC providers working in rural areas.

7.3 Recommendations for researchers

Additional research is needed to estimate the prevalence of childhood cataract and cataract surgical coverage in children to gain accurate data on the burden of childhood cataract in developing countries including India. There is a need to design a surveillance system focused on childhood cataract to record, monitor and assess the progress towards preventing blindness and visual impairment caused by cataract and more details on the surveillance system are described later in this chapter in section under policy recommendations.

There is also a need to prospectively assess the vision improvement in children post cataract surgery, to determine the extent to which different forms of treatment (e.g. refractive correction with or without occlusion therapy) is successful.

As described in Chapter 1, Childhood cataract affects the quality of life (QOL) of the child and their parents and family. A number of health related QOL instruments have been developed for the paediatric population (Davis et al., 2006) and there is also a lot of research on vision-related quality of life, including in children (Gothwal et al., 2015). Recently, a team of researchers reported the need for specific health-related quality of life (HRQOL) and functional vision concerns of children with cataract and parents in developed country (Castaneda et al., 2016). Additional research is needed to develop tools to assess the HRQOL after cataract surgery among the children and the parents in developing countries.

Previous research evidence suggests that there are many post-operative complications after cataract surgery in children including development of amblyopia, glaucoma and other

conditions. Additional research is recommended to prospectively assess the incidence of various complications post cataract surgery and its impact on vision in India.

Childhood cataract surgery requires long term follow up and achieving a good visual outcome after cataract surgery is likely to depend at least in part on the post-operative follow up care in children. Achieving maximum uptake of follow up care is a continuous challenge in even adults for any chronic conditions and it is considered more challenging in children. Additional research is recommended to assess the barriers and enablers associated with the access to follow-up care post childhood cataract surgery in different regions.

Further research is recommended to validate the barriers and enablers questionnaire developed in this research using the TDF framework (see Appendix 5 for details). Programs implemented in wider communities should be developed that target specific behaviours that could bring changes in how childhood cataract and its treatment is perceived to increase the uptake of services by the communities. The impact of implementing such positive behavioural changes program in the community should be investigated using a robust experimental design.

Behaviour change interventions are challenging and to achieve positive outcomes it is recommended that implementation strategies have theoretical bases. However, there are many behaviour change theories (Michie et al., 2014) and it is important for programme planners to select a theory that is appropriate for the behavioural problem that they are trying to change with due consideration given to the setting/ population. The Behaviour Change Wheel (BCW), is a framework that provides programme planners with a comprehensive, coherent, and universal toolkit for intervention design and can be used to guide the choice of an appropriate intervention (Michie et al., 2011).

The BCW consists of 19 pre-existing frameworks of behaviour change in a single interface incorporating a theory of behaviour, intervention functions, and associated policy categories. It is important to choose the specific component of the behavioural model and the intervention functions for achieving better outcomes.

The BCW is based on the COM-B system (Capability, Opportunity and Motivation – Behaviour), which proposes that for any behaviour to occur the individual performing the

behaviour needs to have the physical and psychological capability, the social and physical opportunity and the motivation to do so. The availability of affordable eye care services within reach and access to necessary transportation are examples of physical opportunity to access services. Being part of a society that values and encourages conventional medical treatment rather than following home remedies or superstitions may provide the social opportunity for doing so. Motivation refers to cognitive processes that energize and direct a behaviour and includes reflective motivation, such as conscious decision-making. Any behaviour change intervention may target one or more of these three pre-cursors to behaviour.

For an intervention to be successful, it is critical to understand which of these three components require changing. For example, an intervention designed to motivate people to access eye care services for children is less likely to be effective if the main reason for not accessing the services is a lack of knowledge around eye conditions and the services that are available to treat them. In this case an intervention targeting psychological capability (i.e. Knowledge) would be more likely to lead to success.

There are four steps to develop a theory informed implementaion intervention (French et al., 2012b) which include: identifying the specific behaviour and the target group and secondly using the TDF approach to identify barriers and enablers that need to be addressed. Based on these two factors, the third step is to identify the intervention components that are feasible, relevant to the cultural context and the final step defines the measures of behaviour change.

The findings of this research suggest that there are facilitators and barriers to childhood cataract services which are modifiable such as knowledge, beliefs and consequences and social influences, and this study is an important first step in establishing evidence as a basis for addressing issues on this topic. However, this explanatory study has led to the development of a single questionnaire based on the 14 domains of the TDF and Behavioural change wheel components of the COM-B model (Michie et al., 2011) which has the potential to be used for any eye conditions at the community level. This questionnaire covers the COM-B system, the TDF domains and the meaning of each domain in this context and the various possible questions for each domain.

However, the questionnaire developed from this study needs to be further validated and in future studies aimed at identifying eye health seeking behaviour. The draft questionnaire covering 14 domains as per the revised TDF domains is included in Appendix 5.

Based on the findings from this research a preliminary recommended intervention strategy to achieve behaviour changes with the aim of increasing early uptake of childhood cataract services in India is described in Table 7.1.

Table 7.1 Recommended intervention functions for increasing the timely uptake of childhood cataract services in India

Barrier domains*	**Details of Barriers**	**Target audience**	**COM-B components ** **	**Recommended intervention functions ***
Knowledge	A lack of knowledge of cataract in children, and lack of awareness about the preventive aspects and when to go for surgery.	Parents and carers	Psychological capability	Education
Knowledge	A lack of knowledge relating to cataract surgery and follow up in children.	PECW	Psychological capability	Education
Beliefs about Consequences	A belief that it is acceptable to delay	Parents and carers	Reflective motivation	Education and Modelling

Barrier domains*	Details of Barriers	Target audience	COM-B components **	Recommended intervention functions *
	cataract surgery in children A belief that a visit to babaji (local priest) will cure the cataract in children			
Motivation and goals	No intention to take the child for any routine eye examination, citing time constraints	Parents and carers	Reflective motivation	Education, Incentivisation, and Modelling
Environmental Context and Resources	Economic constraints and limited the feasibility of travelling long distances to seek the treatment	Parents and carers	Physical opportunity	Environmental restructuring, Training, and Enablement
Social Influences	Parents were influenced by what their friends and families did and recommended.	Parents and carers	Social opportunity	Environmental restructuring, training and Enablement

Barrier domains*	Details of Barriers	Target audience	COM-B components **	Recommended intervention functions *
Social Influences	A belief that there are differences in accessing the surgical services based on gender	PECW	Social opportunity	Environmental restructuring, training and Enablement
Nature of behaviour	A belief that it is difficult to practice patching post operatively	Parents and carers	Reflective motivation	Education, Modelling and Enabling
Skills	A lack of awareness and inadequate training in particular about children eye diseases	PECW	Physical Capability	Training

** - COM-B component stands for Capability (Physical capability or Psychological capability), Opportunity (Physical opportunity or Social opportunity), and Motivation (Automatic motivation or Reflective motivation)–Behaviour, represents source of the behaviours and is the core of the BCW

* Recommended intervention functions were identified by the Behaviour Change Wheel (BCW)

This research mainly focused on assessing the barriers and enablers from the parents / carers who have accessed the cataract services for their children. Additional research is required to assess the same at the community level among those who have children with cataract but have not sought surgery, as the associated barriers may be different.

Additional research is needed to further probe on the differences in cataract services utilisation rate by gender. It is important to explore in detail why fewer girls accessed the surgical services compared to boys in their respective age group.

Consanguineous marriage was reported commonly in this research and additional research is required to explore the importance of consanguinity as a cause of blinding eye diseases in children at the population level. Qualitative research to explore behaviours and attitudes towards consanguinity is recommended.

7.4 Recommendations to the participating hospitals

It is recommended to consider revising the policy decision on only offering free surgical service when the child is diagnosed at the community screening, but not when they make a self-referral to the hospital. This policy has contributed to delay in accessing the surgical services in many children due to poor economic conditions of the parents. As discussed in chapter 5, parents wait (as long as 2 to 3 years) for a camp to be organised in their vicinity to access the free services for their child. Considering the importance of early surgery, it is recommended that the hospitals should have a policy that allows parents to walk in any time to get the surgery done for the children rather than waiting for a screening program.

All the participating hospitals have primary eye care workforce which works within the community in providing screening and linking the community for service provision. The hospital should have a policy to train this workforce using a standard curriculum which covers detection and management of eye problems in children. This team's knowledge and their feedback on their work and challenges need to be discussed at regular intervals to provide effective services to the children in the community. It is highly recommended to have one community worker attached to every vision centre focused on children's eye care. This person will be able to work with all stakeholders and catalysts in the community to provide

continuous screening and necessary linkage to service delivery. This will become a model of eye care addressing both inequality and inequity at the community level.

It is recommended that each PEC team should have an active eye care awareness strategy for their respective coverage area focused on different stakeholders like parents and general community and another for the professional community. The professional community includes general health care workers from public and non-governmental sector, education sector and other ophthalmic community working in the region to ensure everyone is aware of various eye problems in children, available treatment and the need for early referral and intervention.

It is recommended that the hospitals should work with the local schools and education department to educate the children towards preventing eye injuries.

The hospital should have a system linked to the medical records to track each child advised for cataract surgery and follow them up with the community eye care team to ensure the child undergoes the surgery as early as possible as advised by the ophthalmologist. It is recommended to implement a follow up system post-surgery to track the children with the aim of achieving maximum visual potential in children.

It is recommended to have a nurse or technician trained in genetic counselling for parents in a consanguineous marriage who attend the hospital for their child with congenital cataract, to offer guidance and advice for further child planning based on the likelihood of increased risk for childhood cataract. Also, it is highly recommended that the hospital team interacting with the parents communicates clearly about the cataract surgery and the follow up requirements and ensures the parents' fear and anxiety towards surgery is addressed (Bronsard et al., 2008).

In addition to these recommendations, previous research indicates that:

1. The hospitals should provide full correction of aphakia either though spectacles, contact lenses or intraocular lenses to all children as soon as possible after cataract surgery for achieving potential visual outcome (Autrata et al., 2005). Surgery should be performed as early as possible after the development of a visually disabling opacity and it is recommended to have standard guidelines for surgery.

2. Simultaneous bilateral cataract surgery has previously been recommended in feasible cases to reduce risks related to anaesthesia and delayed surgery in children and this model has been studied earlier including neonates (Nallasamy et al., 2010).

3. It is also recommended that the hospitals should consider implanting IOL in children with under refractive error correction according to the child's age. Along with additional procedures such as Lensectomy with posterior capsulectomy and anterior vitrectomy to offer a clear visual axis with single operation. Also to prevent secondary cataract, intensive anti-inflammatory therapy are recommended. These strategies are found to be beneficial in cases where children cannot attend regular follow up (Hennig et al., 2013).

It is recommended to all the hospitals to read the policy recommendations discussed in the next section and to pilot some of the strategies within their coverage area. Outcomes should be documented in an attempt to determine how early screening and intervention can be achieved effectively.

7.5 Recommendations for policy decisions

7.5.1 Policy related to Prevention

Paediatric eye injuries prevention strategies

The present research results show that around 24% of the children presenting with cataract had suffered an ocular injury, and this needs some urgent attention. As discussed earlier in chapter 4, safety and awareness programs offered in urban private schools reduced the incidence of eye injuries in children (Gogate et al., 2012). Similarly, there is a need to develop an effective paediatric eye injury prevention system combining legislation, policies, standards, education as part of school curriculum, and personal eye protection to limit exposure to ocular hazards among children as recommended (Hoskin et al., 2016).

7.5.2 Screening for early identification

Neonatal screening for red reflex

Red reflex screening to identify ocular abnormalities during the neonatal period has been found to be effective in identifying cataract, retinoblastoma and other eye abnormalities earlier in children in the developed countries. The early identification and intervention is effective to achieve better visual outcomes. Similar policies are required in developing countries.

In India, eye care programs have an independent structure and engage themselves in blindness prevention activities. The most successful examples are the adult cataract screening programs which have worked very well in reaching the communities independently to organise mass service delivery. However, in the case of children, the number of children requiring cataract services is very low compared to adults and hence the eye care programs setting up an independent screening for new-borns for early identification of cataract and other eye abnormalities may not be cost effective. Working in isolation may have helped to achieve good cataract surgical coverage (CSR, an indicator to measure the cataract surgical coverage in the population) but may not be helpful with other eye conditions which requires networking with other health care providers and other developmental sectors. For refractive errors in children interdisciplinary partnerships between schools and the eye care service delivery providers have helped to screen millions of children enrolled in schools as described earlier in chapter 4 (page 162), discussion section. With the active participation of school teachers in screening the children this method has proven to be cost effective.

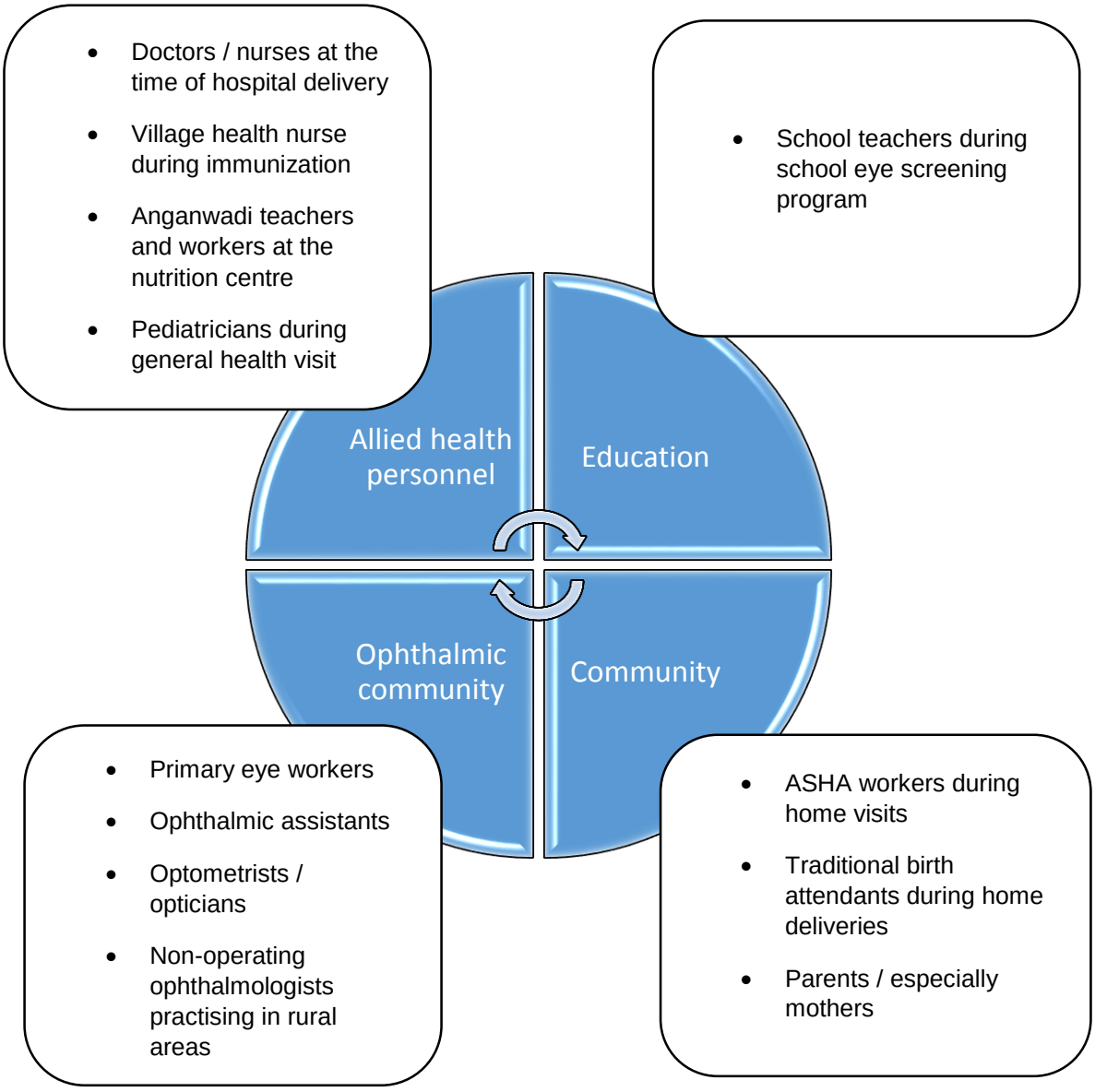
Similarly, the partnership established between neonatal intensive care units and the eye care team has led to the development of retinopathy of prematurity screening in major towns in India. Although this has not extended to the majority of the NICU's in the bigger towns and cities it has potential to do so if the necessary human and other resources are made available. Similar partnerships are required for dealing with childhood cataract with different sectors including health, education, water supply and sanitation sector for achieving effectiveness.

For all hospital births, along with Apgar[13] score, it is highly recommended to include in the policy to screen for a red reflex in children for early identification of eye abnormalities. However, this may again have limited coverage in the developing countries, where around 30 -40% of births are in homes; as described in chapter 4, in this study around 32% of the participants were born at home. For those children who are born at home, the red reflex screening can be recommended during the immunisation by the village health nurses. Each child will be in contact with a nurse for a minimum of 4 times within the 6 months from birth for various immunisations and it will be the best possible time to perform red reflex screening in children.

As discussed in chapter 6, a standardised training programmes are needed for primary health care teams, and these could be managed by programs such as the national program for the prevention of blindness (NPCB) in collaboration with the state and district program committees across the country (Figure 7.2).

[13] A measure of the physical condition of a new-born infant. It is obtained by adding points (2, 1, or 0) for heart rate, respiratory effort, muscle tone, response to stimulation, and skin coloration; a score of ten represents the best possible condition.

Figure 7.2 An integrated primary model for eye screening of young children with the existing human resources



7.5.3 Eye health promotion

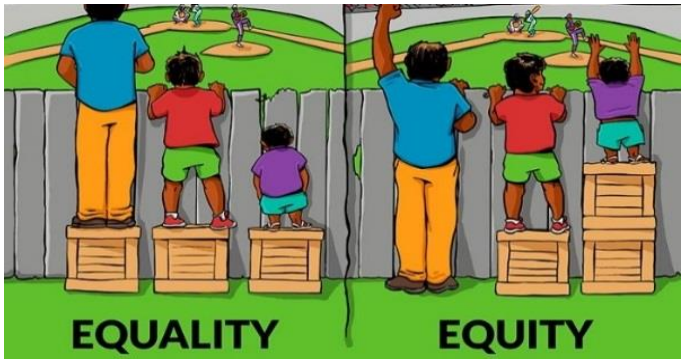
As explained earlier chapter 5 and 6, there is a need to increase awareness among various stakeholders relating to childhood cataract. The NPCB is in a position to prioritise the eye health promotional activities mainly focused on the avoidable blindness conditions in children. Parents and professionals working with children need to be informed that cataracts in children are treatable if intervention is sufficiently early. Also, the eye care professionals

including optometrists, ophthalmic assistants, ophthalmologists and primary eye care providers and other health care providers at the primary level are made aware about the importance of early surgery in children and the follow up requirements after cataract surgery. The present findings indicate that at least some of the primary eye care team believe, incorrectly, that cataract in children is similar to adult cataract and delayed surgery in children will not have any impact on the vision. Awareness and knowledge could lead to better understanding among both parents and providers, which would increase the uptake of routine eye examinations for the early detection and treatment of eye diseases, and thereby reducing visual impairment in this population.

3.4 Inequality and inequity in eye care

The UN Convention on the Rights of the Child (CRC; article 24) *…recognizes the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health "…. all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health… (http://www.unicef.org/why/why_rights.html.)*

According to this convention, every child has the right to access necessary care and adequate infrastructure including trained human resources and fully equipped facilities, which are pre-requisites for addressing any health problem in children. As outlined earlier, the WHO recommends one paediatric ophthalmology service centre for every 10 million people in the population, including at least one specialty trained or oriented ophthalmologist with necessary support team to provide services. However, currently the paediatric ophthalmology service availability is inadequate in India and moreover the existing services are mainly located in urban areas as described in chapter 1, making it more challenging for the rural communities who have the higher burden of diseases. This is an issue across all health problems and the Indian government should take necessary action to bridge both inequality and inequity in service provision between urban and rural areas as described in the picture below.



Source: www.culturalorganizing.org

Also, it is recommended:

1. To create more primary eye care facilities in rural areas which can primarily engaged in screening and provide referral services.
2. To provide transport services similar to those offered for adult cataract screening programs in rural areas for the rural children and their families to access the care in urban areas when referral is given to them.

3.5 Universal eye health coverage

The WHO advocates a global eye health action plan built primarily using the health system approach, which encompasses the integration of eye care programmes into the wider health care system at all levels (primary, secondary, and tertiary) to achieve universal eye health coverage (http://www.who.int/blindness/actionplan/en/). For India to achieve the universal eye health coverage advocated by WHO, it is recommended to start this integration of children's eye care activities at the primary level with the wider health care system in India as discussed earlier about Neonatal screening for red reflex.

3.6 Monetary support

Currently government funds are provided to NGOs to support adults but not cataract treatment. Funding should be allotted specifically for childhood cataract treatment. It is recommended to have clear guidelines from NPCB on how to apply for such grant in aid support for childhood cataract surgery.

3.7 Information and Monitoring system

Surveillance monitoring at the state and national level

Currently there are systems to assess the performance and quality of outcomes of cataract surgeries in adults. Regular performance monitoring and the quality of the service provided in conjunction with the assessment of disease prevalence and backlog allows the program team and the policy makers to make appropriate decision on further implementation. However, there have been no such standard methods to monitor the progress in providing the childhood cataract services. There is a need to create a system to identify all childhood cataract surgeries performed by age, region as well as by gender to monitor the progress and identify gaps in the utilisation of existing services in different regions and this was recommended for any developing countries which is working towards reducing blindness in children due to avoidable causes (Courtright et al., 2008).

Creation of special interest group

Currently India is battling to reduce the overall blindness of which cataract and refractive errors are the leading causes, and hence they have high priority under the blindness prevention program. Recently, diabetic retinopathy is gaining interest due to the increased prevalence of diabetes in the country. Children's eye care is addressed currently by the school eye screening program. More emphasis needed to address issues such as childhood cataract, ROP, glaucoma and retinoblastoma and all of these conditions require wider collaboration among other health care providers. It is highly recommended to set up special interest groups within the country to focus on children's eye care to reduce avoidable blindness and visual impairment in children. This group should focus on the following areas:

- creating more evidence related to childhood cataract
- developing standard guidelines for defining childhood cataracts and
- Criteria for childhood cataract surgery and follow up recommendations for reducing blindness and visual impairment in children.
- In addition, this group should actively work on advocating policy changes for implementation across the country.

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9 Appendices

9.1 Appendix 1: Ethics approval letters

9.1.1 City, University of London

CITY UNIVERSITY LONDON

School of Health Sciences

Research Office
Northampton Square
London EC1V 0HB

Tel: +44 (0) 20 7040 5704

www.city.ac.uk

Ref: PhD/15-16/01

29 June 2015

Dear Sheela / Catherine / John

Re: Barriers and enablers for the uptake of childhood cataract services

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

[redacted]

Alison Welton
Research Governance Officer

[redacted]

9.1.2 H V Desai Eye Hospital, Maharashtra

PBMA'S H. V. DESAI EYE HOSPITAL

"We reach out and care"

HVD/EC/30/2015

Date: - 27.7.2015

To,
Dr. Anushree Kaduskar
[redacted]

Subject: Ethics Committee approval letter.

Study Title: - Barriers and enablers for the uptake of childhood cataract services.

Dear Dr,

With reference to the aforementioned study and your submission letter dated 13th July 2015 meeting of the Ethics Committee, PBMA's H. V. Desai Eye Hospital was held on 23rd July 2015 14:30 hrs at PBMA's H. V. Desai Eye Hospital's board room.

Following study documents were reviewed and approved by Ethics Committee

1. Study Protocol.
2. Informed consent form in Marathi & English
3. Patient information sheet in Marathi & English
4. Questionnaires.
5. CV of Principal investigator & Co Investigator

The list of Ethics Committee Members who attended the meeting on 23rd July 2015 is as follows:-

Sr. No.	Name	Gender	Qualification	Designation	Affiliation
1	Lt. Gen. (Retd) Dr. M.A. Tutakne	Male	MBBS, DVD, MD	Scientist	No
2	Dr. G. T. Panse	Male	MD. Ayurveda & Medicine PhD. Drug chemistry.	Pharmacologist	No
3	Dr. V. S. Padbidri	Male	MBBS, PhD (Micro)	Ethics Committee Member	No
4	Dr. Sudheer Kher	Male	MBBS, DCP(Dip. Clinical Pathology, MD (Microbiology)	Basic Medical Scientist	No

5	Maj. Gen. (Retd) Dr. Vijay Tilak	Male	MBBS, DPH, DIH, MD(PSM)	Clinician	No
6	Mrs. Vidya Krishna Lavekar	Female	B.Sc.	Philosopher	No
7	Shri. Pradip Bimalkhedkar	Male	BE Mech. PGDBM, Diploma information Technology	Lay person	No
8	Dr. Sangeeta Wagh	Female	MS. DNB. (Ophthal.)	Clinician	No
9	Mr. Bastimal Solanki	Male	B.Com.	Social Worker	No
10	Adv. Sangita Kulkarni	Female	BLS ,LLB	Legal expert	No.
11	Mr. Umesh Trivedi	Male	B. Pharm .	Pharmacologist	No
12	Dr. Kuldeep Dole	Male	MS((Ophthal.)) M.Sc. (Community Eye university of London)	Scientist	Yes

The study document was approved with 12 votes in favor of the study as against zero votes against the study.
It is to be noted that none of your study members or yourself were present during the meeting.

The full composition of this ethics committee is as below:

Sr. No	Name	Gender	Qualification	Designation	Affiliation
1	Lt. Gen. (Retd) Dr. M.A.	Male	MBBS, DVD, MD	Scientist	No
2	Dr. G. T. Panse	Male	MD. Ayurveda & Medicine PhD. In Drug Chemistry	Pharmacologist	No
3	Dr. Sudheer Kher	Male	MBBS, DCP (Dip. Clinical Pathology, MD (Microbiology)	Basic Medical Scientist	No
4	Dr. V. S. Padbidri	Male	MBBS, PhD (Micro)	Ethics Committee Member	No
5	Shri. V. P. Rane	Male	BA, B.Com, LLB, IAS	Legal expert	No
6	Adv. Sangita Kulkarni	Female	BLS ,LLB	Legal expert	No
7	Maj. Gen. (Retd) Dr. Vijay Tilak	Male	MBBS, DPH, DIH, D(PSM)	Clinician	No
8	Mrs. Vidya Krishna Lavekar	Female	B.Sc.	Philosopher	No
9	Dr. Sangeeta Wagh	Female	MS. DNB. (Ophthal.)	Clinician	No
10	Mr. Bastimal Solanki	Male	B.Com.	Social Worker	No

11	Shri. Pradip Bimalkhedkar	Male	BE Mech. PGDBM, Diploma information Technology	Lay person	No
12	Mr. Umesh Trivedi	Male	B. Pharm.	Pharmacologist	No
13	Dr. Kuldeep Dole	Male	MS (Ophthal.) M.Sc. (Community Eye university of London)	Scientist	Yes

Please note that you are required to follow the requirements given below for this study:

- Do not implement any deviation from, or change to, the protocol approved by this ethics committee without the prior written approval of this ethics committee. Deviations/ changes to the approved protocol may be implemented without prior approval of this ethics committee only when necessary to eliminate immediate hazards to subjects or when changes involve only logistical or administrative aspects of the trial [e.g. change of study monitor(s), telephone numbers(s)].

Promptly report following points to ethics committee:

- Any changes to or deviations to the protocol approved by this ethics committee that you may implement to eliminate hazards to the trial subjects.
- All serious adverse events.
- New information that may affect adversely the safety of the subjects or the conduct of the trial.

This ethics committee is organized and operates according to the requirements of ICH –GCP, Schedule Y and requirements of the Indian Council of Medical Research (ICMR).

- You are requested to inform the Ethics Committee of any amendments in the protocol for which fresh approval need to be taken.
- You are required to submit a progress report every six months and a final study report at the end of the study.
- The approval of the study will extend throughout the entire study.

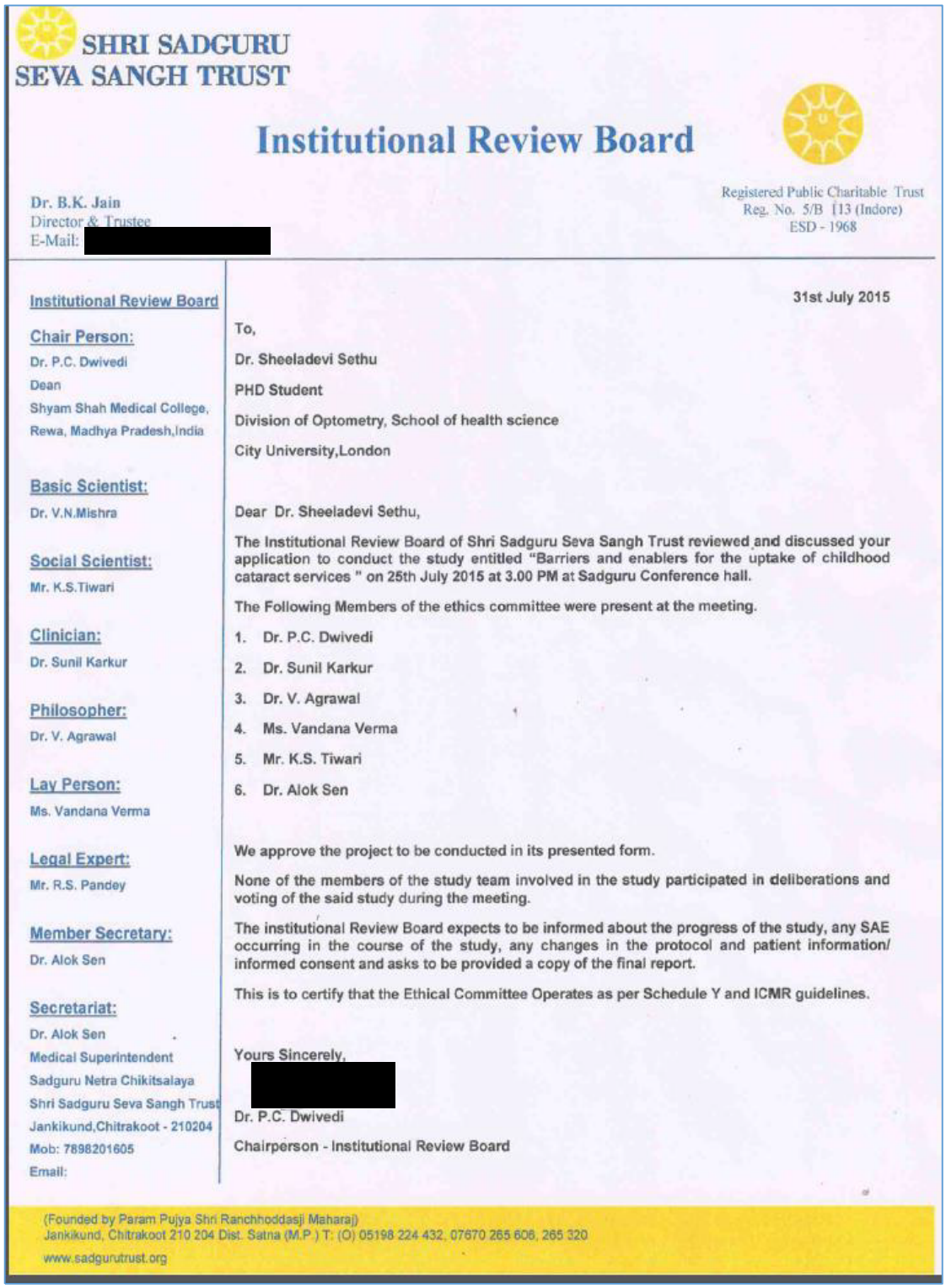
Thanking you,

[redacted]

Dr. Kuldeep Dole

Secretary
Ethics Committee
H.V. Desai Eye Hospital, Pune

9.1.3 Shri Sadguru Seva Sangh Trust, Madhya Pradesh



SHRI SADGURU
SEVA SANGH TRUST

Institutional Review Board

Registered Public Charitable Trust
Reg. No. 5/B 113 (Indore)
ESD - 1968

Dr. B.K. Jain
Director & Trustee
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Social Scientist:
Mr. K.S.Tiwari

Clinician:
Dr. Sunil Karkur

Philosopher:
Dr. V. Agrawal

Lay Person:
Ms. Vandana Verma

Legal Expert:
Mr. R.S. Pandey

Member Secretary:
Dr. Alok Sen

Secretariat:
Dr. Alok Sen
Medical Superintendent
Sadguru Netra Chikitsalaya
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Email:

31st July 2015

To,

Dr. Sheeladevi Sethu

PHD Student

Division of Optometry, School of health science

City University,London

Dear Dr. Sheeladevi Sethu,

The Institutional Review Board of Shri Sadguru Seva Sangh Trust reviewed and discussed your application to conduct the study entitled "Barriers and enablers for the uptake of childhood cataract services " on 25th July 2015 at 3.00 PM at Sadguru Conference hall.

The Following Members of the ethics committee were present at the meeting.

1. Dr. P.C. Dwivedi
2. Dr. Sunil Karkur
3. Dr. V. Agrawal
4. Ms. Vandana Verma
5. Mr. K.S. Tiwari
6. Dr. Alok Sen

We approve the project to be conducted in its presented form.

None of the members of the study team involved in the study participated in deliberations and voting of the said study during the meeting.

The institutional Review Board expects to be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/ informed consent and asks to be provided a copy of the final report.

This is to certify that the Ethical Committee Operates as per Schedule Y and ICMR guidelines.

Yours Sincerely,

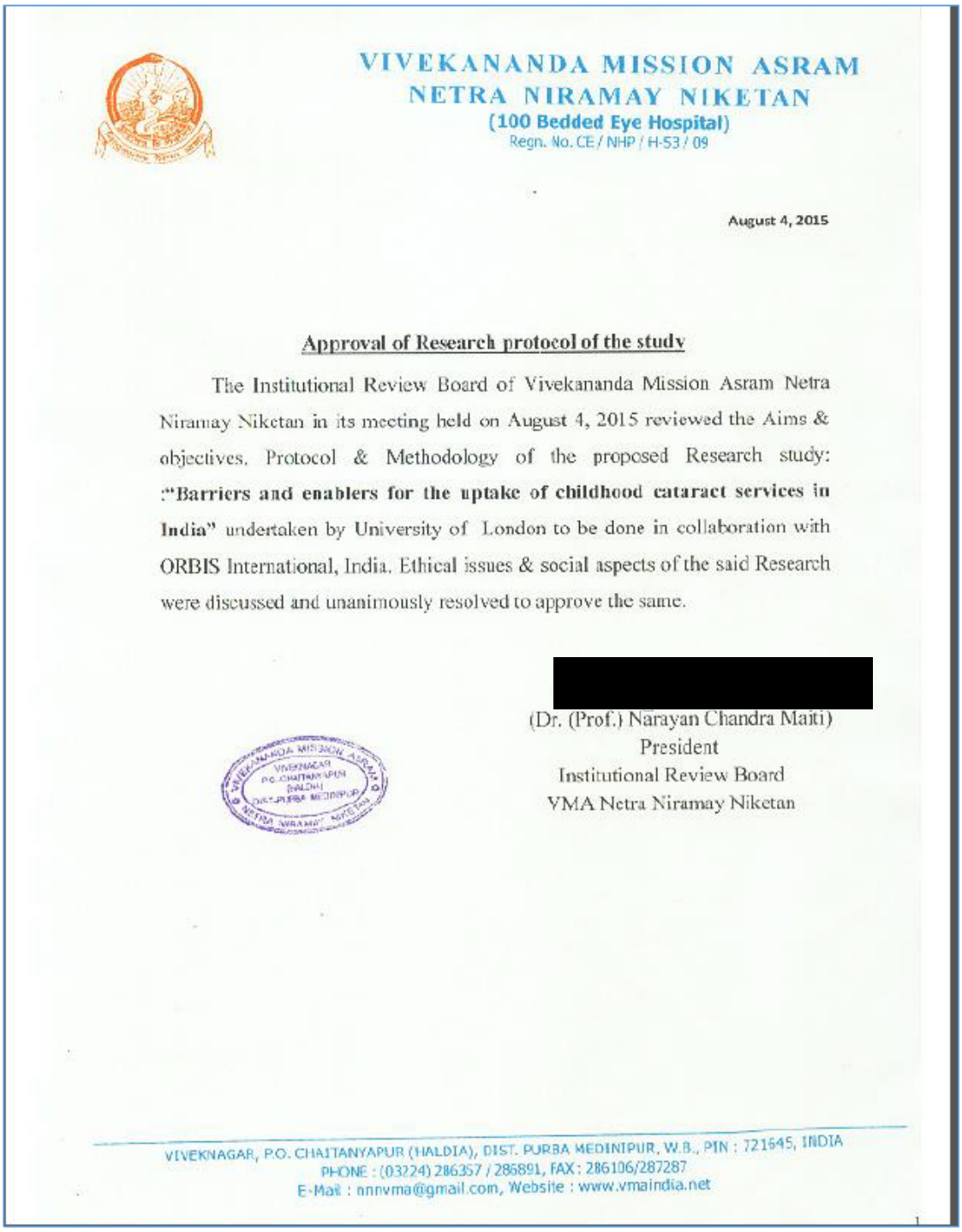
[redacted]

Dr. P.C. Dwivedi

Chairperson - Institutional Review Board

(Founded by Param Pujya Shri Ramchhoddasji Maharaj)
Jankikund, Chitrakoot 210 204 Dist. Satna (M.P.) T: (O) 05198 224 432, 07670 265 606, 265 320
www.sadgurutrust.org

9.1.4 Vivekananda Mission Ashram Netra Nirmay Niketan, West Bengal



VIVEKANANDA MISSION ASRAM
NETRA NIRAMAY NIKETAN
(100 Bedded Eye Hospital)
Regn. No. CE / NHP / H-53 / 09

August 4, 2015

Approval of Research protocol of the study

The Institutional Review Board of Vivekananda Mission Asram Netra Niramay Niketan in its meeting held on August 4, 2015 reviewed the Aims & objectives, Protocol & Methodology of the proposed Research study: **"Barriers and enablers for the uptake of childhood cataract services in India"** undertaken by University of London to be done in collaboration with ORBIS International, India. Ethical issues & social aspects of the said Research were discussed and unanimously resolved to approve the same.

[redacted]
(Dr. (Prof.) Narayan Chandra Maiti)
President
Institutional Review Board
VMA Netra Niramay Niketan

VIVEKNAGAR, P.O. CHAITANYAPUR (HALDIA), DIST. PURBA MEDINIPUR, W.B., PIN : 721645, INDIA
PHONE : (03224) 286357 / 286891, FAX : 286106/287287
E-Mail : nnnvma@gmail.com, Website : www.vmaindia.net

9.1.5 Little Flower Hospital and Research centre, Kerala

Phone : EPABX : 3954000, 3096666, 2452546, 2452547
2452548, 2456146, 2456147

Fax No. : 91 - 484 - 2452646
E-mail : enquiry@lfhospital.org
admin@lfhospital.org
website:www.littleflowerhospitaltrustangamaly.org

LITTLE FLOWER HOSPITAL & RESEARCH CENTRE

OWNED BY ARCHDIOCESE OF ERNAKULAM
Post Box : 23, Angamaly - 683 572, Kerala, India.

Approved by I M C for Senior House Surgeoncy
vide letter No. M C I - 18 (3) 78 - Med / 28460 dated 27 - 3 - 1979
Accredited training centre for National Board of Examinations
Approved training centre of Royal College of Surgeons, UK
Research Centre Recognised by Mahatma Gandhi University
A Unit of the Federation of the Ophthalmic Research & Education Centre

Date: 19-08 -2015

No EC/18/2015

Sub. Research Topic Approval by the Ethical Committee

The Ethical Committee held on 27.07.2015 discussed the Topic **"Barriers and enablers for the uptake of childhood cataract services"** presented by Dr. Sanita Sathyan of Ophthalmology for **Orbis International** to be conducted in Little Flower Hospital and Research centre and approved the research topic.

Members of the Ethical Committee Present:

Adv. Binu John Moolan (Chairman)

Rev. Fr. (Dr.) Paul V. Madan

Dr. Deepu Jacob Chacko (Pharmacologist)

Dr. Ashok Menon (Neurologist)

Mr. P. V. Thomas

Dr. Stigimon

Mr. Jose Antony, M.S.W., PhD (Sociologist)

Sr. Ranitta MSJ

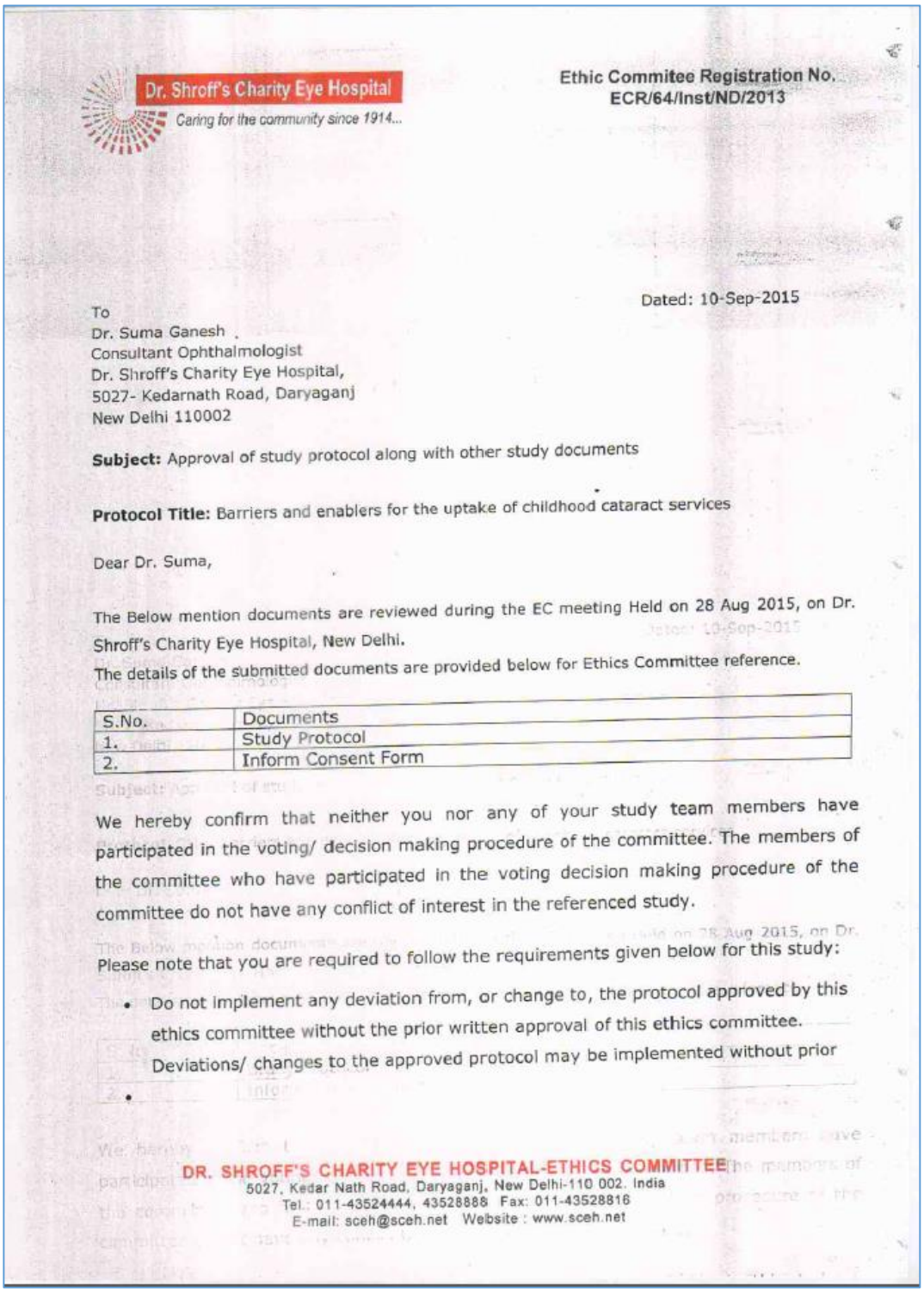
Fr. Baiju Kannampilly (Secretary)

[redacted]

Fr. Baiju Kannampilly

Secretary

9.1.6 Dr Shroff's Charity Eye Hospital, New Delhi



Dr. Shroff's Charity Eye Hospital
Caring for the community since 1914...

Ethic Commitee Registration No.
ECR/64/Inst/ND/2013

Dated: 10-Sep-2015

To
Dr. Suma Ganesh .
Consultant Ophthalmologist
Dr. Shroff's Charity Eye Hospital,
5027- Kedarnath Road, Daryaganj
New Delhi 110002

Subject: Approval of study protocol along with other study documents

Protocol Title: Barriers and enablers for the uptake of childhood cataract services

Dear Dr. Suma,

The Below mention documents are reviewed during the EC meeting Held on 28 Aug 2015, on Dr. Shroff's Charity Eye Hospital, New Delhi.
The details of the submitted documents are provided below for Ethics Committee reference.

S.No.	Documents
1.	Study Protocol
2.	Inform Consent Form

We hereby confirm that neither you nor any of your study team members have participated in the voting/ decision making procedure of the committee. The members of the committee who have participated in the voting decision making procedure of the committee do not have any conflict of interest in the referenced study.

Please note that you are required to follow the requirements given below for this study:

- Do not implement any deviation from, or change to, the protocol approved by this ethics committee without the prior written approval of this ethics committee. Deviations/ changes to the approved protocol may be implemented without prior

DR. SHROFF'S CHARITY EYE HOSPITAL-ETHICS COMMITTEE
5027, Kedar Nath Road, Daryaganj, New Delhi-110 002. India
Tel.: 011-43524444, 43528888 Fax: 011-43528816
E-mail: sceh@sceh.net Website : www.sceh.net

Dr. Shroff's Charity Eye Hospital
Caring for the community since 1914...

Ethic Commitee Registration No.
ECR/64/Inst/ND/2013

approval of this ethics committee only when necessary to eliminate immediate hazards to subjects.

Promptly report following points to ethics committee:

- Any changes to or deviations to the protocol approved by this ethics committee that you may implement to eliminate hazards to the research subjects.
- All serious adverse events.

This ethics committee is organized and operates according to the requirements of ICH - GCP requirements of the Indian Council of Medical Research (ICMR) and scheduled Y requirements.

- You are requested to inform the Ethics Committee of any amendments in the protocol for which fresh approval need to be taken.
- You are required to submit a progress report annually and a final study report at the end of the study.
- The approval of the study will extend throughout the entire study and the EC will reissue the approval in case of any amendment upon submission.

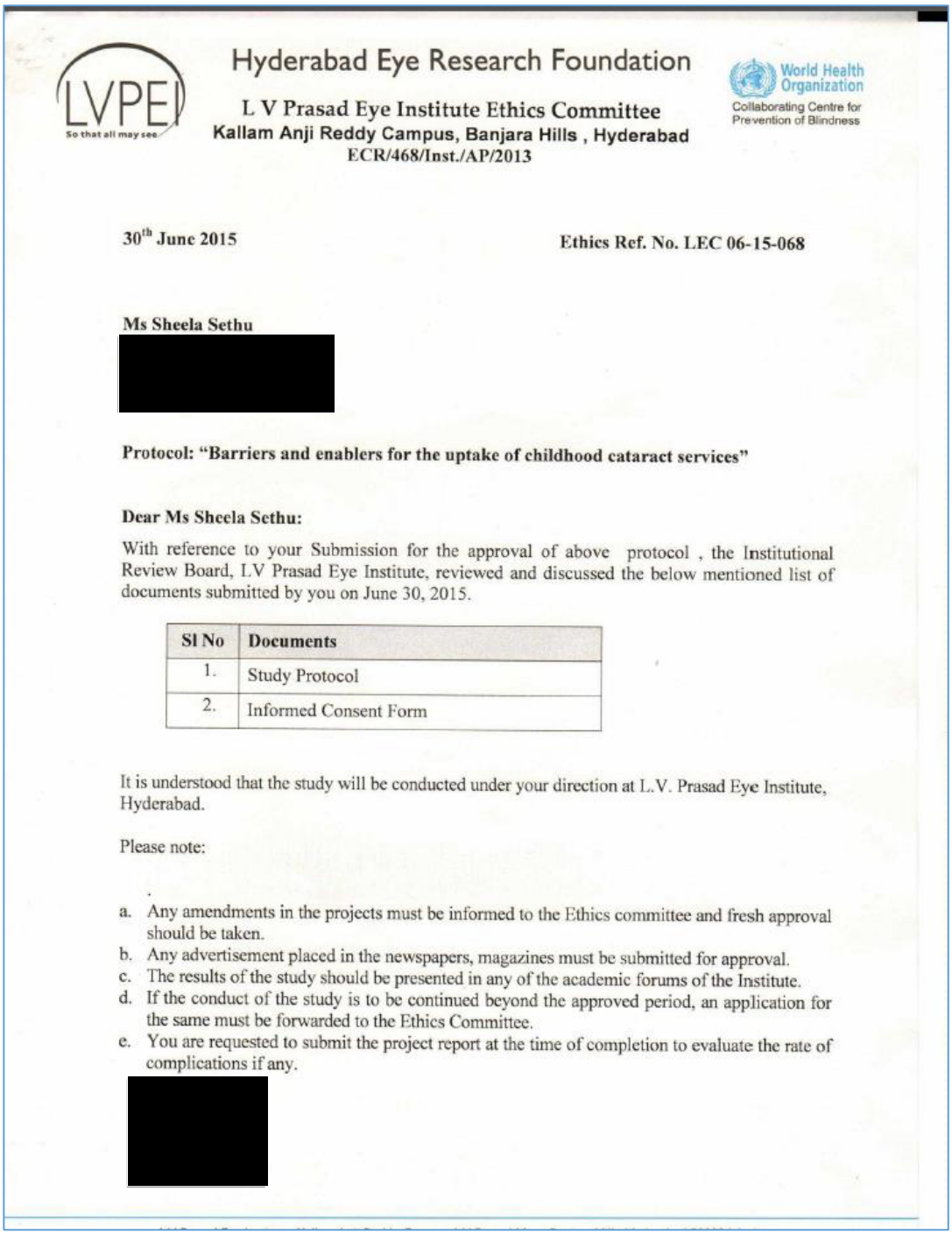
Thanking you,

[redacted]

A. K. Arora
Member Secretary

DR. SHROFF'S CHARITY EYE HOSPITAL-ETHICS COMMITTEE
5027, Kedar Nath Road, Daryaganj, New Delhi-110 002. India
Tel.: 011-43524444, 43528888 Fax: 011-43528816
E-mail: sceh@sceh.net Website : www.sceh.net

9.1.7 L V Prasad Eye Institute, Telangana and Andhra Pradesh



Hyderabad Eye Research Foundation

L V Prasad Eye Institute Ethics Committee
Kallam Anji Reddy Campus, Banjara Hills , Hyderabad
ECR/468/Inst./AP/2013

World Health Organization
Collaborating Centre for Prevention of Blindness

30th June 2015

Ethics Ref. No. LEC 06-15-068

Ms Sheela Sethu
[redacted]

Protocol: "Barriers and enablers for the uptake of childhood cataract services"

Dear Ms Sheela Sethu:

With reference to your Submission for the approval of above protocol , the Institutional Review Board, LV Prasad Eye Institute, reviewed and discussed the below mentioned list of documents submitted by you on June 30, 2015.

Sl No	Documents
1.	Study Protocol
2.	Informed Consent Form

It is understood that the study will be conducted under your direction at L.V. Prasad Eye Institute, Hyderabad.

Please note:

a. Any amendments in the projects must be informed to the Ethics committee and fresh approval should be taken.
b. Any advertisement placed in the newspapers, magazines must be submitted for approval.
c. The results of the study should be presented in any of the academic forums of the Institute.
d. If the conduct of the study is to be continued beyond the approved period, an application for the same must be forwarded to the Ethics Committee.
e. You are requested to submit the project report at the time of completion to evaluate the rate of complications if any.

[redacted]

f. You should report all serious adverse events to the Ethics Committee within 48 hours of their occurrence and evaluate the rate of complications if any.

The following members of the Ethics Committee were present at the meeting held on **June 30, 2015 at 3:00pm, Godrej Hall, Level 6, L V Prasad Eye Institute, Hyderabad 500 034**

Name	Qualification	Designation/Title	Affiliations as to the Institution Yes/No
Justice T N C Rangarajan	M.A, B.L.	Retired Judge	No
Dr Sayan Basu	M.S	Clinician	Yes
Dr Sreedevi Yadavalli	M.A, M. Phil, PhD	Lay person	Yes
Dr B R Shamanna	MD, DNB (MCH), DNB (SPM), MSc.	Basic Medical Scientist	No
Dr Savitri Sharma	MD, FAMS	Basic Scientist	Yes
Dr. Subhabrata Chakrabarti	PhD	Basic Scientist	Yes

It is hereby confirmed that neither you nor any of the members of the study team participated in the decision making/voting procedures. After consideration, the committee has approved the study for a period of one year. (Until closing hour of June 29, 2016)

We hereby confirm that, the Institutional Review Board, L V Prasad Eye Institute is organized and operates as per GCP (Good Clinical Practice) and applicable Indian regulations.

Yours Sincerely,

[redacted]

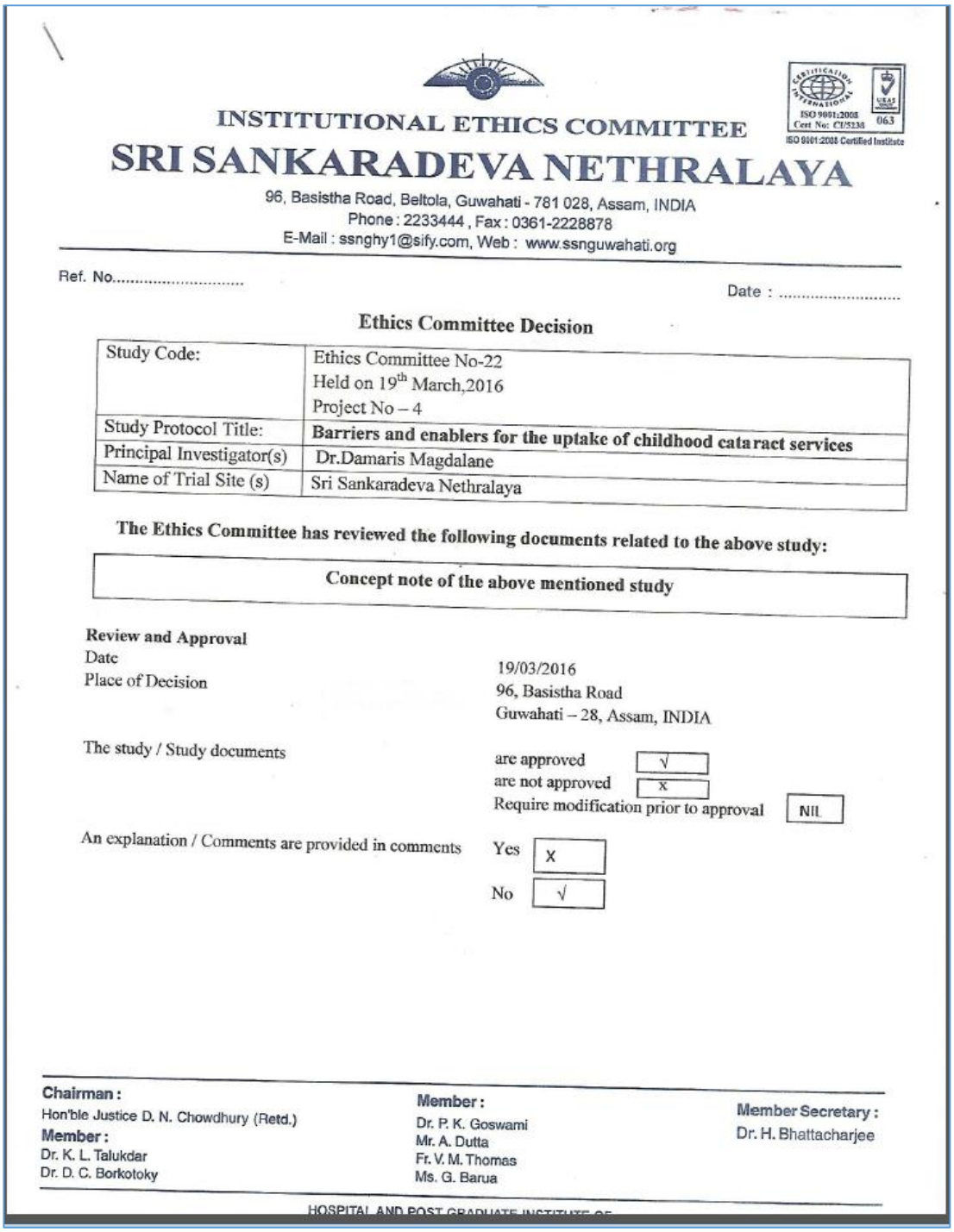
Justice T N C Rangarajan
Chairperson
Ethics Committee

Ethics Committee
L. V. Prasad Eye Institute
Kallam Anji Reddy Campus
L.V. Prasad Marg, Banjara Hills
Hyderabad-500 034

[redacted]

Sayan Basu, MS,
Member Secretary
Ethics Committee

9.1.8 Sri Sankaradeva Nethralaya, Assam



INSTITUTIONAL ETHICS COMMITTEE

SRI SANKARADEVA NETHRALAYA

96, Basistha Road, Beltola, Guwahati - 781 028, Assam, INDIA
Phone : 2233444 , Fax : 0361-2228878
E-Mail : ssnghy1@sify.com, Web : www.ssnguwahati.org

ISO 9001:2008 Cert No: CI/5238 063
ISO 9001:2008 Certified Institute

Ref. No.....

Date : .....

Ethics Committee Decision

Study Code:	Ethics Committee No-22 Held on 19th March,2016 Project No – 4
Study Protocol Title:	**Barriers and enablers for the uptake of childhood cataract services**
Principal Investigator(s)	Dr.Damaris Magdalane
Name of Trial Site (s)	Sri Sankaradeva Nethralaya

The Ethics Committee has reviewed the following documents related to the above study:

Concept note of the above mentioned study

Review and Approval

Date: 19/03/2016

Place of Decision: 96, Basistha Road, Guwahati – 28, Assam, INDIA

The study / Study documents
- are approved: √
- are not approved: X
- Require modification prior to approval: Nil

An explanation / Comments are provided in comments
- Yes: X
- No: √

Chairman :
Hon'ble Justice D. N. Chowdhury (Retd.)

Member :
Dr. K. L. Talukdar
Dr. D. C. Borkotoky

Member :
Dr. P. K. Goswami
Mr. A. Dutta
Fr. V. M. Thomas
Ms. G. Barua

Member Secretary :
Dr. H. Bhattacharjee

HOSPITAL AND POST GRADUATE INSTITUTE OF

Comments

NIL

The Ethics Committee is working according to ICH – GCP and applicable laws and regulations.

[redacted]

19/03/2016
Date of issue

Justice D N Chowdhury (Retd.)
Chairman, Institutional Ethics Committee

Ethics Committee Membership List

Name	Profession	Affiliation	Voting during this meeting	Member of the study
Hon. Justice D N Chowdhury	Former Judge	Outside Member	Yes	No
Mrs. G Barua	Ex Principal, Handique Girl's College	Outside Member	Yes	No
Dr. P K Goswami	Professor, Dept. of Ophthalmology, NEIGRIHMS, Shillong	Outside Member	Yes	No
Mr. Ajoy Dutta	Social Activist	Outside Member	Yes	No
Fr. V. M. Thomas	Director, Don Bosco Institute	Outside Member	Absent	Absent
Dr. K. L. Talukdar	HoD, Anatomy, GMCH	Outside Member	Yes	No
Prof. D C Borkotoky	Retired Professor & Head of Medicine, GMCH	Outside Member	Yes	No
Dr. M. Lahkar	HoD, Pharmacology, GMCH	Outside Member	Yes	No
Mr. Subhash Chandra Keyal	Assistant Solicitor general of India, Guwahati High Court	Outside Member	Absent	No
Dr. H Bhattacharjee	Ophthalmologist	Inside Member	Yes	No

9.2 Appendix 2: STUDY PARTICIPANT INFORMATION SHEETS

9.2.1 Barriers and enablers for the uptake of childhood cataract services – Questionnaire based study

We would like to invite you to take part in this study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Cataract is one of the major causes of visual impairment and blindness in children. The condition is treatable in most cases if the necessary treatment is received on time. The aim of this study is to find out why some children receive treatment late, by asking carers and eye care providers. This will help us to provide information that may improve future childhood cataract services in India as well as in other developing countries.

Who is involved in organising this research?

This research study is organised and conducted by Sheeladevi Sethu, a PhD student at City University London, supervised by Dr Catherine Suttle and Prof. John Lawrenson

Why have I been invited?

You have been invited because you have a child who is undergoing cataract surgery during the period from Nov 2015 to Feb 2016.

Do I have to take part?

No. Participation in this research is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part your experience will help the health professionals gain a better understanding of the factors associated with uptake of Childhood cataract. If you do decide to participate, you will be contacted to meet with the researcher/ interviewer and asked to sign a consent form. If at any point you wish to discontinue, you are free to withdraw from the study at any time without giving reasons. Taking part in this study will not affect the care that your child receive now or in the future.

What will happen if I take part?

If you choose to participate, you will be asked a set of questions about the cataract services for your child. The questions will be asked face to face (an interview) over 20 to 30 minutes, in which you can leave at any time you wish. With your permission, you may be contacted

later by phone if necessary for follow up details of your child's treatment. The questions ask about your socio economic details, your child's birth and details of the eye problems and most importantly the process and issues you encountered to reach the hospital for cataract surgery. We will also access the medical records of your child, to access information about your child's eye health, treatment procedures and the outcome

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks in participating in this research. The only disadvantage of the study is the time required to take part in this study. We value your time and utilize it to gather meaningful information.

What are the possible benefits of taking part?

Your participation in this research may contribute to improved future cataract services for children in India as well as in other developing countries.

Will my taking part in the study be kept confidential?

All information collected from you will be kept strictly confidential at all times. This means that no one reading about the study will be able to recognise you as a participant. All names used in the interview will be deleted or reported using a code.

Who has reviewed the study?

This study has been approved by City University London *School of Health Sciences* Research Ethics Committee

What will happen to results of the research study?

The information collected will be used for the preparation of research reports and the results of this research will be published in scientific journals and conferences without revealing personal identification. The information will also be used for planning strategies to address the gaps in accessing cataract services by children in India and other developing countries

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw from the study without an explanation or penalty at any time.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team or report to the local (India) contact given below. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform

them that the name of the project is: "**Barriers and enablers for the uptake of childhood cataract services"**

Local contact in India:

Dr G N Rao
[redacted]

Dr Rahul Ali
[redacted]

You could also write to the Secretary at:

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London EC1V 0HB
Email: [redacted]

Further information and contact details

Researcher: Sheeladevi Sethu, PhD Student
Email: [redacted]

Please do not hesitate to contact the researcher if you require further details or have any questions about the research. The researcher is very happy to answer them for you.

Thank you for reading this leaflet and considering taking part in the study.

9.2.2 Barriers and enablers for the uptake of childhood cataract services – In-depth interviews

We would like to invite you to take part in this research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Cataract is one of the major causes of visual impairment and blindness in children. The condition is treatable in most cases if the necessary treatment is received on time. The aim of this study is to find out why some children receive treatment late, by asking carers and eye care providers. This will help us to provide information that may improve future childhood cataract services in India as well as in other developing countries.

Who is involved in organising this research?

This research study is organised and conducted by Sheeladevi Sethu, a PhD student at City University London, supervised by Dr Catherine Suttle and Prof. John Lawrenson

Why have I been invited?

You are invited to participate in this study as one of your child has been diagnosed with cataract and advised for surgical treatment. We are interviewing parent /carer whose child has and hasn't completed cataract surgery.

Do I have to take part?

No. Participation in this research is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part your experience will help the health professionals gain a better understanding of the factors associated with uptake of Childhood cataract.
If you do decide to participate, you will be contacted to meet with the researcher/ interviewer and asked to sign a consent form. If at any point you wish to discontinue, you are free to withdraw from the study at any time without giving reasons. Taking part in this study will not affect the care that your child receive now or in the future.

What will happen if I take part?

If you choose to participate, you will be asked a set of questions about the process involved in accessing the cataract services for your child. You will be interviewed once and the interview will last between 1 to 1.5 hours, in which you can leave at any time you wish. The interview will be based on the questions you answered for us previously, and will help us to

understand the various issues you encountered in diagnosis of your child's cataract, and in accessing the hospital for cataract surgery. We will also access the medical records of your child, to access information about your child's eye health, treatment procedures and the outcome.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks in participating in this research. The only disadvantage of the study is the time required to take part in the interview. We value your time and utilize it to gather meaningful information.

What are the possible benefits of taking part?

Your participation in this research may contribute to improved future cataract services for children in India as well as in other developing countries.

Will my taking part in the study be kept confidential?

All information collected from you will be kept strictly confidential at all times. This means that no one reading about the study will be able to recognise you as a participant. All names used in the interview will be deleted or reported using a code.

Who has reviewed the study?

This study has been approved by City University London *School of Health Sciences* Research Ethics Committee

What will happen to results of the research study?

The audio taped information collected will be transcribed and used for the preparation of research reports and the results of this research will be published in scientific journals and conferences without revealing personal identification. The information will also be used for planning strategies to address the gaps in accessing cataract services by children in India and other developing countries

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw from the study without an explanation or penalty at any time.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team or report to the local (India) contact given below. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform

them that the name of the project is: "**Barriers and enablers for the uptake of childhood cataract services"**

Local contact in India:

Dr G N Rao

Dr Rahul Ali

You could also write to the Secretary at:

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London EC1V 0HB
Email:

Further information and contact details

Researcher: Sheeladevi Sethu, PhD Student
Email:

Please do not hesitate to contact the researcher if you require further details or have any questions about the research. The researcher is very happy to answer them for you.

Thank you for reading this leaflet and considering taking part in the study.

9.2.3 Barriers and enablers for childhood cataract services – Focus group discussion

We would like to invite you to take part in this research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Cataract is one of the major causes of visual impairment and blindness in children. The condition is treatable in most cases if the necessary treatment is received on time. The aim of this study is to find out why some children receive treatment late, by asking carers and eye care providers. This will help us to provide information that may improve future childhood cataract services in India as well as in other developing countries.

Who is involved in organising this research?

This research study is organised and conducted by Sheeladevi Sethu, a PhD student at City University London, supervised by Dr Catherine Suttle and Prof. John Lawrenson

Why have I been invited?

You are invited to participate in this study as your role involves screening children with eye problems and counselling carers to take their child for necessary treatment at the hospitals. We will be organizing a focused discussion along with your colleagues. There will be around 7 to 9 participants per session and we are planning to conduct 3 to 4 sessions in different regions in India.

Do I have to take part?

No. Participation in this research is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part your experience will help the health professionals gain a better understanding of the factors associated with uptake of Childhood cataract.
If you do decide to participate, you will be contacted to meet with the researcher/ interviewer and asked to sign a consent form. If at any point you wish to discontinue, you are free to withdraw from the study at any time without giving reasons.

What will happen if I take part?

If you choose to participate, you will be asked to be part of a discussion along with 6 or 7 other eye health providers to share your opinions based on your experience of the factors associated with the uptake of cataract services for children. The discussion will be facilitated

by the researcher based on pre-designed topic guides and the interview will last between 1 to 1.5 hours, in which you can leave at any time you wish.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks in participating in this research. The only disadvantage of the study is the time required to take part in this study. We value your time and utilize it to gather meaningful information.

What are the possible benefits of taking part?

Your participation in this research may contribute to improved future cataract services for children in India as well as in other developing countries.

Will my taking part in the study be kept confidential?

All information collected from you will be kept strictly confidential at all times. This means that no one reading the study will be able to recognise you as a participant. All names used in the interview will be deleted or reported using a code.

Who has reviewed the study?

This study has been approved by City University London *School of Health Sciences* Research Ethics Committee

What will happen to results of the research study?

The audio taped information collected will be transcribed and used for the preparation of research report and the results of this research will be published in scientific journal and conferences without revealing the personal identification. Also the information will be used for planning strategies to address the gaps in accessing cataract services by the children in India and other developing countries

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw from the study without an explanation or penalty at any time.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team or report to the local (India) contact given below. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: "**Barriers and enablers for the uptake of childhood cataract services"**

Local contact in India:

Dr G N Rao
L V Prasad eye Institute
[redacted]

Dr Rahul Ali
Country Director – India programs
[redacted]

You could also write to the Secretary at:

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London EC1V 0HB
Email: [redacted]

Further information and contact details

Researcher: Sheeladevi Sethu, PhD Student
Email: [redacted]

Please do not hesitate to contact the researcher if you require further details or have any questions about the research. The researcher is very happy to answer them for you.

Thank you for reading this leaflet and considering taking part in the study.

9.3 Appendix 3: Study Questionnaire

Barriers and enablers for the uptake of childhood cataract services

Subject Study ID: Date:

Name of the Study Centre: Centre ID:

Hospital MR No: Treatment Category: Paying/ Non-paying

Date of Birth &Age: Gender:

Location: Urban/ Semi-rural/ Rural District: State:

Contact no of Parent/Guardian: …….

A. Parent Information:

Relationship	Religion	Age	Education	Occupation	Reported monthly income	Respondent (Yes/No)	Consanguineous marriage? (Yes/No)
Father							
Mother							
If the respondent is other than the parents; please provide the following information							
Relationship	Religion	Age	Education	Occupation			

Religion:

1 – Hindu

2 – Christian

3 - Muslim

4 – Others, specify

Education:

1 – No education;

2 – 5 years of school education;

3 – 6 to 12 years of education;

4 –Bachelor's Degree

5 – Master's Degree and above

Occupation:

1 – Not working

2 – Agriculture/farmer

3 – Casual labourer/ Coolie

4 – Government job

5 – Private Job

6 – Business

7 – Professional job

8 – Others, specify

Income:

1 - Nil

2 – <INR 5,000

3 – INR 5,001 -10,000

4 – INR 10,001 -20,000

5 - >INR 20,001

B. Child details:

Birth place: Birth order: No of siblings:

Family history of cataract? Yes /No

C. Recognition:

1. At what age was the child's eye problem identified?
    g. Within 1 month from birth
    h. 1 -6 months
    i. >6 -12 months
    j. >1 -3 years
    k. >3 -10 years
    l. Above 10 years -
2. Who first identified the problem?
    a. Mother
    b. Father
    c. Neighbour/ relative/older sibling
    d. Health worker, specify…….
    e. Others, specify…….
3. What changes were noticed in your child's eye?
    a. Cloudiness
    b. Eye rubbing
    c. Crossed eye
    d. Poor vision
    e. Others specify……
4. Any self-treatment taken? Yes / No

    If yes, specify the treatment……
5. Who first decided to take the child to the hospital?
    a. Father
    b. Mother
    c. Both
    d. Other elders at home
    e. Others, specify.....
6. Whom did you see first for your child's eye problem?
    e. General physician
    f. Paediatrician
    g. Ophthalmologist
    h. Others specify……..
7. When did you visit an eye hospital after recognising the problem?
    a. Immediately
    b. Within one month
    c. >1 – 3 months
    d. >3 – 6 months
    e. More than 6 months
8. If you accessed the eye hospital more than 3 months from recognition, specify the reasons for the delay (tick all that apply and for each response specify the level of importance from 1- low importance to 5 -high importance)

a.	Child too young for Surgery	1	2	3	4	5
b.	Problem is not very severe	1	2	3	4	5
c.	Distance	1	2	3	4	5
d.	Economic reasons	1	2	3	4	5
e.	No one to accompany	1	2	3	4	5
f.	Fear of surgery	1	2	3	4	5

g. Language problem 1 2 3 4 5
h. No one to look after others in the family 1 2 3 4 5
i. Child had other health problems 1 2 3 4 5
j. Any other problem…… 1 2 3 4 5
k. Didn't know, where to go 1 2 3 4 5

9. At the hospital, how urgently was surgery advised?
    a. As early as possible
    b. Within 3 months
    c. After 3 months
10. If the surgery happened later than the advised period, specify the reasons for the delay (tick all that apply and for each response specify the level of importance from 1 - low importance to 5 - high importance)
    a. We didn't get the appointment for surgery 1 2 3 4 5
    b. Child is too young for surgery 1 2 3 4 5
    c. Problem is not very severe 1 2 3 4 5
    d. Distance 1 2 3 4 5
    e. Economic reasons 1 2 3 4 5
    f. No one to accompany 1 2 3 4 5
    g. Fear of surgery 1 2 3 4 5
    h. Language problem 1 2 3 4 5
    i. No one to look after others in the family 1 2 3 4 5
    j. Child had other health problems 1 2 3 4 5
    k. Any other problem…… 1 2 3 4 5

D. Access issues:

1. What is the distance between your home and hospital?

2. What was the cost of travel per person for a round trip?

3. How many people accompanied the child on this visit?

4. How much total money has this surgery cost you (including all the expenses)?
    a. Food per day…….No of days.....
    b. Surgery cost…….
    c. Medicines……..
    d. Loss of wages: Per day per person……..No of days.....No of persons:.....
    e. Accommodation charges per day……No of days.....
    f. Other costs specify……..

Information to be obtained from medical records:

E. Surgery details:

1. Child Weight:……...Kgs

Particulars	Left Eye	Right Eye
2. Diagnosis	Congenital / Developmental/ Traumatic / None	Congenital / Developmental/ Traumatic / None
3. Pre op Vision (If vision is not recorded mention as NA)		
4.Fixing at Light	Very good / Poor	Very good / Poor
5.Identifying objects at closer distance	Yes / No	Yes/No
6.Probable cause	Familial/ Rubella and other infections / Idiopathic/ Traumatic/ Others specify……..	Familial/ Rubella and other infections / Idiopathic/ Traumatic/ Others specify……..
7.Any co-morbidities: Yes/ No	If yes, specify	
8. Other disabilities: Yes / No	If yes, specify	
9. Any syndromes: Yes / No	If yes, specify	
Surgical details:		
10.Surgery Eye:	Left Eye / Right Eye	
11.Cataract Type:	Total (no view) / Partial	
12.Type of surgery	With IOL / Without IOL With PPC / With PPC No PPC / No PPC	
13.Any intra-operative complications: Yes / No	If yes, specify……	
14.Any post-operative complications: Yes/ No	If yes, specify…….	

If the child is undergoing second eye surgery, obtain the following details for the previous eye:

Date of surgery: Cataract type:

Type of surgery: Surgery eye:

Pre-op vision: LE RE

Post-op vision:

Date of first post-op follow up:

Any intra-operative complications:

Any post-operative complications:

9.4.3 Conference presentations

1. **S Sheeladevi,** JG Lawrenson, CM Suttle. Barriers and enablers for the uptake of childhood cataract services. **Poster presentation** Annual Doctoral research conference, City University of London, April 2015
2. **S Sheeladevi,** JG Lawrenson, AR Fielder, CM Suttle. Global burden of Childhood Cataract: A Systematic review. **Oral presentation.** British Congress on Optometry and Visual Science (BCOVS), City University of London, Sep 2015.
3. **S Sheeladevi,** John G Lawrenson, Ramesh Kekunnaya, Rahul Ali, Rishi R Borah, Catherine Suttle. Interval between recognition and surgery for childhood cataract across India: a multicentre observational study. **Oral Presentation.** BCOVS, University of Ulster, Sep 2016.
4. **S Sheeladevi,** JG Lawrenson, AR Fielder, CM Suttle. Global prevalence of Childhood Cataract: A Systematic review. **Oral presentation** on International Agency for Prevention of Blindness (IAPB) general assembly, Durban, South Africa, Oct 2016.
5. **S Sheeladevi,** John G Lawrenson, Ramesh Kekunnaya, Rahul Ali, Rishi R Borah, Catherine Suttle. Interval between recognition and surgery for childhood cataract across India: a multicentre observational study. **Poster Presentation,** International Agency for Prevention of Blindness (IAPB) general assembly, Durban, South Africa, Oct 2016
6. **S Sheeladevi,** John G Lawrenson, Ramesh Kekunnaya, Rahul Ali, Rishi R Borah, Catherine Suttle. Barriers to childhood cataract services across India. A mixed methods study using the Theoretical Domains Framework (TDF) of behaviour change. **Poster Presentation,** Association for Research in Vision and Ophthalmology (ARVO), Baltimore, USA, May 2017.
7. **S Sheeladevi,** John G Lawrenson, Ramesh Kekunnaya, Rahul Ali, Rishi R Borah, Catherine Suttle. Knowledge and perspectives of primary eye care providers regarding childhood cataract services: a qualitative study**. Poster Presentation** BCOVS, University of Plymouth, Sep 2017

9.5 Appendix 5: Draft questionnaire to assess the eye health seeking behaviour at the community level using TDF approach			
COM -B	**Domain Name**	**Content**	**Relevant questions**
Psychological capability	1. Knowledge	An awareness about the condition	In general, what do you know about children's eye problems, particularly cataract in children?
Physical capability	2. Skills	Ability or proficiency acquired through practice	To what extent do you feel you can recognise eye problems in a child? Example: cataract, squint, refractive error
Reflective motivation	3. Social professional role and identity (self-standards)	Set of behaviours and qualities of an individual in social context	From your perspective: How can awareness be created among the community about children's eye health? What approaches can be used to ensure that all children with cataract are treated as early (young) as possible?
Psychological capability	4. Beliefs about capabilities	Views about the respondent's ability/ capability to perform the target behaviour (to ensure early cataract treatment)	How easy or hard to complete the necessary treatment for a child with cataract? How would you rate the capability of the eye care team in respective hospital?

			What is your opinion on the quality of eye care service available near your home town?
Automatic motivation	5. Optimism	Confidence that things will happen for the best	To what extent do you feel your child's eye problem will be resolved?
Reflective motivation	6. Beliefs about consequences (anticipated outcomes /attitude)	Views about the existing beliefs and its consequences	Are there any self-practices adopted for treating cataract in your community? What cultural beliefs about cataract in children exist in your community? Do you feel surgery is the only option for treating cataract in children? Are there any risks involved in cataract surgery in children?
Automatic motivation	7. Reinforcement	Increasing the probability of the target behaviour by arranging a dependent relationship, or contingency, between the behaviour and a given stimulus	Has anyone motivated you to seek childhood eye care services services? Has anyone influenced your decision to go for surgery? And Who?

Reflective motivation	8. Intentions	Conscious decision to perform a behaviour or a resolve to act in a certain way	When do you think the child with cataract should be taken to an eye specialist? What is the earliest age a child can undergo surgery for cataract? Would it be ok to delay surgery until the child is grown up? Are you willing to take your child to the doctor for follow-up care, whenever it is advised? Is cataract surgery the only aspect of treatment? If yes, how have you been informed of this? If not, what other aspect of treatment is required?
Reflective motivation	9. Goals	Mental representations of outcomes or end states that an individual wants to achieve	How soon you would like to complete the surgery for your child? What is your expectation on the outcome of the surgery?
Psychological capability	10. Memory, attention and decision process	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives	How do you choose a hospital for your child's eye care needs?

			Is there any problem in remembering the post-operative instructions to be followed at home for your child?
Physical opportunity	11. Environmental context and resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour	What factors prevent or help you in accessing cataract services for children at the community level and at the hospital level?
Social opportunity	12. Social influences (norms)	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours	Is there any gender disparity in accessing childhood cataract services? What is the decision-making process in your household for accessing children's eye care services?

			What kind of social support (at the family and community levels) is available or required to access childhood cataract treatment early?
Automatic motivation	13. Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event	Do you have any fears about your child's eye surgery? What was your feeling when your child was advised to undergo surgery?
Psychological capability	14. Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions	From your perspective, how can it be made easier for children with cataract to access cataract treatment at the earliest possible age?

9.6 Appendix 6: Selected quotes from qualitative data

9.6.1 Complete Enablers results, sorted by TDF Domain

(P – Parents; M – Mother; F – Father; GP – Grandparents; FG – Family group)

TDF Domain	Identified Theme	Frequency (*n* transcripts)	Interviewees (Roles, *n*)	Sample Quotes
Beliefs about consequences	Outcome Expectancies	6	GP (2), P (3), M (1)	I know that after operation lens is given and the vision comes back. It gets cured (ref Id 10) It's not a good idea to delay the surgery. I feel the eye will get weaker if the surgery is delayed. It is better to get operated at the right time for a better vision. (ref Id 22) I asked the doctor. He said that it happens to some new-born babies. He suggested to get the surgery done at the earliest. Otherwise the problem may increase. (ref Id 29)
	Attitudes	17	GP (1), P (8), M (1), F (7)	We felt … but, then we thought it is about the eyes and eyes are everything. So it is necessary. My elder brother also came. We quickly took the decision to go ahead with the surgery and admitted her. (ref Id 10) Surgery should be done at the earliest. Age should not be a barrier. Whenever there is a problem, surgery should be done. (ref Id 10) No whenever the doctor says, after 15 days or one month accordingly will come ….. Difficulty is there. But I need to look after my son. I can't look at the difficulty. (ref Id 11) We have been told to come every fifteen days. We did not say no. There should not be negligence from our side. His life has to be successful … (ref Id 14) 90% of the responsibility lies with us so we have to take the responsibility and take the child to the doctor in time and take the treatment and follow the instructions of the doctor. (ref Id 2) Every child must go for an eye check-up and it should be done as soon as possible after birth. (ref Id 22) Yes-yes, it is very good to check the eyes of the children. I am thinking about my other children who are ok now… but there is no harm in getting a routine test done. (ref Id 6)

	Reinforcement	11	GP (1), P (3), M (1), F (6)	The doctors told that the surgery should be done immediately as with time the situation of the child's eye sight would worsen. They showed me children aged as little as 4 months on whom surgery had been done and tried to convince me. They said that it is quite normal. After knowing all this, I became confident and went ahead with the surgery. (ref Id 4) Yes, I was afraid. Such a small child… but then the doctor said that if surgery is not done early then his second eye might also get affected. This eye might get totally useless. (ref Id 29) No whenever the doctor says, after 15 days or one month accordingly will come ... Difficulty is there. But I need to look after my son. I can't look at the difficulty. (ref Id 11) Once he had fever so I took him to the doctor. He was a general doctor. He suggested to get his eyes checked. When his eyes were checked it was told that he had cataract. They suggested this place. (ref Id 18) Initially on hearing about surgery I was afraid that she is a little girl … going for the surgery … But then we thought we cannot decide over what the doctor has said. We should do what he has suggested…We decided to go for the surgery. (ref Id 3)
	Beliefs	3	GP (1), F (2)	Cataract is not god's curse. In many people after cataract surgery they can see. I believe in god and pray every day in the morning and I believe god blesses us…(ref Id 1) God is there, doctor is there…. Should not be any problem... (ref Id 7) My mother and father suggested to get the surgery done here… By God's grace everything will be alright. So we brought her here. (ref Id 16)

	Perceived risk/threat	8	GP (1), P (3), F (4)	We wanted to get it done at the earliest possible. I also heard that cataract bursts. So we wanted to do it at the earliest. (ref Id 10) Necessary to get checked within 1-2 months of knowing about it. Because of the delay, it (the problem) would not reduce…Will keep on increasing. Whatever the disease may be …(ref Id 15) Yes, without delay surgery should be done… the problem might increase. It is possible that it might not be cured by surgery even. (ref Id 16) We thought there is a risk in surgery… but, whatever happens we should go ahead with the surgery so that she could get her eyesight back and see better. (ref Id 10)
	Priority	9	M (3), P (2), F (4)	Yes, I think there is still some treatment to be continued after surgery. We have to come here a few times for her check-up. Well, even if it is a problem coming for follow up, I can't ignore as it's my responsibility. (ref Id 10) Doctor said that spectacle will be required. So, I am getting it done here. There is not difficulty. Now my child is able to see. I will feel good to come hoping that he would see better. (ref Id 13) I take precautions so that my child does not get hurt during playing with other children. I don't let him mingle too much with others. I have been doing this since I came to know about his eye problem. (ref Id 4) He goes to school. Today he had a test. I gave a leave application to the school and brought him today. I thought this is important and should be done at the earliest. Earlier also he had to skip school... (ref Id 23)
	Anticipated regret	1	F (1)	If he cannot see then I must get him treated. Otherwise when he grows up he will blame us that we spoiled his eye…(ref Id 27)

	Sensitisation	8	M (2), P (3), F (2), GP (1)	Meetings can be arranged in the village to discuss these issues. The meetings could be arranged through the village head or can be conducted in the village primary school where all the parents should be called. These things should be discussed in that meeting. If people are told in such meetings, many people will be aware. (ref Id 10) We can also conduct awareness programs during the fairs at the village. Health exhibitions can be conducted and knowledge on childhood cataract could be given to the villagers. (ref Id 10) In the villages eye camps are held for older people. Doctors come there. They identify the cataracts and take them for surgery. The camp is held once in a year. But they do not check the children. Nobody knows or understands…. Yes it would be very good to check the children in the camps. No need to go here and there. It can happen near our home. (ref Id 11)
	Appraisal / review	3	M (1), P (2)	Before the surgery if we would keep anything, say a toy… in front of them, they would not react. But after the surgery when the bandage was removed, we put a pen in front of him and he immediately grabbed the pen! That was probably the biggest moment of my life … That something is visible now. At that point I felt that we were going in the right direction... (ref Id 18) I am aware of the problem of my child, I realised that the child is not operated on time, she will go blind totally and the eye will become fully white. Whenever we talk to her earlier she used to move her eyes and now she focuses on the person talking to her. (ref Id 2)
Environmental context and resources	Health care facility	4	P (1), F (2), GP (1)	Yes, the doctor examined and saw all the reports and suggested to get the surgery done quickly. So I admitted her immediately as the surgery was done free of cost. (ref Id 3) So when I came here, I had a referral slip with me from the community screening, where it was written ‘contact counter no 4’. So I went to the counter no 4 where the registration was done and then whatever was required these people went ahead with their work and prepared the file. (ref Id 5) We live near a sugar factory where there is a government hospital. We been there and checked the eyes and they advised cataract surgery. Since we were aware about this hospital we came directly to this hospital, as there was no need to ask any one. (ref Id 1)

	Person X environment interaction	9	P (3), F (4), M (2)	Well, previously there was problem of education in the village. But now people are getting educated and if there is a problem, people do go to hospital. There is nothing such as applying home remedies (ref Id 10) People have become more aware nowadays. There are so many programs running in the villages, the ASHA worker is there, she keeps on meeting and talking to people. (ref Id 10) Yes, some people don't know that even small children could get cataract. Now in our village everyone has come to know. This should be publicized. Now that we know this, we have to tell in our village… also if it comes on TV or newspaper it would be useful. (ref Id 14) I had sent him to coaching for studies. So when the teacher ask him to repeat something he would see elsewhere [not having eye contact]... diagonally. They advised us to take him to the hospital to check his eyes... (ref Id 9)
	Environment	3	F (1), GP (2)	Publicity can be done through the TV. In villages also everyone watches TV. It is not possible to go to every house and do this. Now if someone comes to us… we can suggest to go to the doctor. Other way is to go to the villages and tell people…(ref Id 29)
	Economic	1	F (1)	Yes, I will come as many times the doctor calls for follow-up. Yes, my daughter and wife both come with me .I don't care about the expenses. INR 100 to come, another 100 to go. It takes about two and half hours by bus and three hours by auto. (ref Id 7) The doctor said that it was Cataract. No, we didn't hear about it occurring to new born babies. Then we searched it on the internet and came to know that it happens to new born babies too. (ref Id 29)

Social influences	Social support	39	P (14), F (14), GP (6), M (5)	As we are nearer to the grandchildren and live with them it becomes our responsibility. If baby has fever we take them to the hospital so it's our responsibility. Last time the baby had cough and cold we took the medicines from the doctor from here. (ref Id 1) Our father or uncle is there… They are the elders. In case of this child, her grandparents were also involved along with other family members and a common decision was made. (ref Id 3) In the rural areas people don't have money. So, major decisions are taken after the family members sit together and decide on where the money will be arranged from and how. Sometimes neighbours and / or relatives are also involved. (ref Id 3) I had heard from many people that there are good eye specialists in this town. I tried to find out who knows about this place and took his support and brought him along with me to this hospital. (ref Id 4) Government has given aadhar card that gives us eligibility for getting concession. (ref Id 1) There is one lady who lives in our locality and she gave one free spectacle for my granddaughter… (ref Id 1) We live in the village. So we have to come and stay in an acquaintance's place in the city... we live in a joint family… so my in laws take care of my other children when I am at the hospital. (ref Id 10) For the last three four years I know about the hospital … my villagers know about it. They suggested me to go here. So I came on my own… not through the camp. (ref Id 15) When we go back with our daughter after surgery, many people come to see her. So we will tell them that if your child has any eye problem, you should go to the nearest eye doctor. (ref Id 16) In school, my children always need to sit in the front bench to see the board. We informed the school and they cooperate always. (ref Id 18) Yes, we will go and inform the villagers. Actually, this is how it happens in the villages. Whoever knows, has to give proper suggestions or accompany to come here. (ref Id 3) Two times camp was organized. I got two of my children treated through the camp. (ref Id 20)

	Social norms / culture	19	P (8), F (3), GP (2), M (6)	Well, there is problem of education in the village. But now people are getting educated and if there is a problem, people do go to hospital. There is nothing such as applying home remedies etc.… (ref Id 10) There are some people who believe in taking village medicines, jari-buti [herbal extracts] … some people. But nowadays mostly people are educated, they know and go to the hospital. (ref Id 14) We make no difference whether it is a boy or a girl. Our daughter does not have any problem. But we got her examined. (ref Id 18) Among our relations and neighbourhood too there is no difference. The boys and girls are treated equally. The place where we stay is very good. No one discriminates. (ref Id 20) We thought about her career … Better if it is done in the right age. It is very important for a child. Especially a girl child. (ref Id 22) We both together take decisions in our family. In other families, in general the father is busy and away from home. The mother spends more time with the child and takes good care. So she could decide. (ref Id 22) I take the decision as a mother and my husband doesn't say anything. Even in the neighbourhood as well men's do not have time … they are busy with their work. Children's issues need to be looked after by their mothers. (ref Id 23) No… see my brother has two daughters. There is no problem. Daughter is no less than anyone. If we bring them up properly, they would compete with the boys. If we give proper education, show the right way, then it will be fine …. (ref Id 32) Yes. There is no difference between sons and daughters. I have four daughters and two sons. Rather I love my daughters more than my son. I don't know what kind of environment they would be in after marriage. (ref Id 23) Everyone has different thoughts. I think that even if I am doing labour job, my child should not do this. He should do some better job. So I would forego my wages to bring my child for check up to make sure his eye sight is good. (ref Id 5) Whoever is senior in the family takes the decision (ref Id 11)

	Change agents	10	P (5), F (2), GP (2), M (1)	Decision nowadays both take together. People have become more aware nowadays. There are so many programs running in the villages, the ASHA worker is there, she keeps on meeting and talking to people. (ref Id 10) We keep roaming around the villages. So we need to talk about this. So that if anyone is suffering with eye problems, she/he should be taken to the hospital at the earliest. Home remedies should not be used. (ref Id 10) I provide tuitions to the children. If I find anyone having a problem I suggest to go to the doctor and follow the doctor's advice. (ref Id 10) You (The hospital) are here. But we come to you. So your publicity will happen through us. We go back and tell people that the doctors at this hospital are good, it has the best facilities. (ref Id 16) See, education has to be increased. As they (the parents) get educated, they will change, their thinking will change. (ref Id 19) It is necessary to get an eye examination done …even if the child eyes are normal. In our country during the time of birth itself it should be done once by the doctor in the hospital. (ref Id 29)
Emotions	Fear	6	P (1), F (2), GP (2), M (1)	I had a doubt whether it will get cured or not? Just thought of quickly going to the hospital. (ref Id 1) I felt scared…I thought his future should not be wasted. I asked the doctor again. He said that a lens will be fitted and it would cause no harm. Then, I said ok. Let the surgery be done… (ref Id 18) I had heard from people that if cataract is not treated the child can become blind. I got afraid and came straight to the doctor. (ref Id 19) I am always scared … I keep holding their hands that the eyes should not be hurt. Both my husband and I take a lot of care about our children. We don't let them go alone anywhere, we don't neglect about their medicines or anything. We keep them near us. (ref Id 20) In between I was a little scared, people scared us that something or other would happen. But I am fully satisfied now and the rest is in God's hand. (ref Id 6)

	Positive effect	13	P (5), F (5), M (3)	We felt scared but then we thought it is about the eyes and eyes are everything. So surgery is necessary. (ref Id 10) I felt very bad. Previously only older people would get it. Now it has started among young children as well. So I thought that I have to get him operated. . (ref Id 14) I realised that the child is not operated on time, she will go blind totally and the eye will become fully white. (ref Id 2) My children who use to seeing with crossed eyes could see straight now. Others seeing only things up close earlier, could also see the distant things. I feel relieved that my children are able to see well than before. (ref Id 20) When the doctor told about surgery, I came to this hospital thinking of trying to get the child cured through medicines as his age too less. I did not want at all to go ahead with the surgery. But here the doctors told that the surgery should be done immediately as with time the situation of the child would worsen. They showed me children aged as little as 4 months on whom surgery had been done and tried to convince me. They said that it is quite normal. After knowing all this, I became confident and went ahead with the surgery. (ref Id 4) The doctor said that surgery will be done and your child will become totally 'fresh'. Then I said, ok I want my child to be 'fresh' … then I was tension free and came here and got the surgery done. (ref Id 5) I am telling you from my heart that in future if God willing I am able to do something, I want to help this place with all my heart. I want to help this place. I am so satisfied and happy. And I also tell people that if they have any problem they should come here. (ref Id 6) I did not know about this. They told in the school, I was not there. No I was not scared. I thought that the doctors are there. So why should I fear. So many are there in the hospital. So I did not fear (ref Id 8)

	Anticipated regret	2	P (1), F (1)	Not only once. I would suggest yearly once children eyes and all other check-ups should be done. If we ignore and think that everything is fine, it might happen that when there is really a problem we would regret that we should have done it before and control it. (ref Id 18) In the villages…old people go for cataract surgery when it is 'ripe'. And then this is a small child… I felt pity. I thought it is better to do it now in the beginning itself to save my child. (ref Id 7)
Skills	Parents skill in recognition	2	P (1), GP (1)	Her mother first noticed something white in the eyes. But I was avoiding thinking that it would go away on its own …(ref Id 10) Mothers can closely watch the child for his eye movements and identify if there is any eye problem. (ref Id 29)
	Competence of the hospital staff	1	P (1)	If we come to know about anyone with eye problem, we will suggest them to come to this hospital. We have seen that the employees here are very helpful by nature. I have never faced any problem here. Once you reach here, get yourself registered at the counter, then you don't have to worry for anything further. This is my experience here. (ref Id 10)
Social professional role and identity	Social role	6	P (5), F (1)	We keep roaming around the villages. So we need to talk about this. So that if anyone is suffering with eye problems, she/he should be taken to the hospital at the earliest. Home remedies should not be used. (ref Id 10) I provide tuitions to the children. If I find anyone having a problem I suggest to go to the doctor and follow the doctor's advice. (ref Id 10) If there is any eye problem, they should come to this hospital. If someone doesn't know, he has to be accompanied. Now those who have got the treatment, they have to tell the other people and help them. (ref Id 3) We will go and inform the villagers. Actually this is how it happens in the villages. Whoever knows, has to give proper suggestions or accompany to come here. (ref Id 3)
	Organisation role	3	F (1), P (1), GP (1)	There should be camps for the children so that the parents would become aware and the children would get care. It will be good for all. Such camps are never organized. People don't take children for examination on their own. Because they have no idea that children could have eye problems. They can't think of it. (ref Id 18) If the camp is held regularly, all the disease problems will be solved. (ref Id 5)

Motivation and goals	Certainty of the intention	29	F (10), P (11), GP (3), M(5)	Yes, we would. We make no difference whether it is a boy or a girl. Our daughter does not have any problem. But we got her examined. (ref Id 18) No, never we will arrange marriage for our children within the relatives. Now that we know … We did marry because we didn't know. (ref Id 18) There is no difference between sons and daughters. I have four daughters and two sons. Rather I love my daughters more than my son. I don't know what kind of environment they would be in after marriage. (ref Id 23) It is necessary to get an eye examination done … even if the child eyes are normal. In our country during the time of birth itself it should be done once by the doctor in the hospital. (ref Id 29) The first doctor whom we met had told that he has got cataract since birth. After knowing this I have concentrated only on his treatment so that he could be able to see well. (ref Id 4) There are no pressing issues for me other than my child now. I will bring my child for follow up as per the instructions(ref Id 4) Everyone has different thoughts. I think that even if I am doing labour job, my child should not do this. He should do some better job. So I would forego my wages to bring my child for check up to make sure his eye sight is good. (ref Id 5) I think that my child has grown up, he is eight and half years old but he could not do anything. But this should not happen with anyone else. You should show (the doctor) somewhere or other. This morning itself there was a phone call. A boy in my relations … I will try and help them to get their son treated (ref Id 5) I thought that my daughter is young now. If she gets good treatment, her life will be better. That's why we decided about this place because no other place would be better than this. God willing, I hope that we won't need to bring her here again. (ref Id 6) It is our duty to come timely for follow up. This is important for my child. No problem with work. Whichever date is given, we come. Sometimes we can't come at the right time, but we definitely come on the given date. (ref Id 6) Every child should be checked before birth even when they are inside mother's womb… the doctor should see if there is any problem in the eyes. if not at least they need to get checked after birth(ref Id 7)

	Intention	18	F (6), P (6), FG (2), M(4)	We saw in six months. But actively we started working on it when she started walking at about 9-10 months of age. (ref Id 10) The child's life needs to be improved. (ref Id 14) We have been told to come every fifteen days. We did not say no. There should not be negligence from our side. His life has to be successful …(ref Id 14) For both of us sons and daughters are equal. (ref Id 20) If he cannot see then I must get him treated. Otherwise when he grows up he will blame us that we spoiled his eye. (ref Id 27) She is a sick child. Whatever the difficulties are there, even if we have to borrow money we have to manage and come for her. (ref Id 3) She is my only child and I would like her eye sight to be normal. (ref Id 30) Whether it is a son or a daughter, there is no difference. Both are same. (ref Id 32) I take precautions so that my child does not get hurt during playing with other children. I don't let him mingle too much with others. I have been doing this since I came to know about his eye problem. (ref Id 4)

	Intrinsic motivation / service intention	8	F (3), P (3), M(2)	We keep roaming around the villages. So we need to talk about this. So that if anyone is suffering with eye problems, she/he should be taken to the hospital at the earliest. Home remedies should not be used. (ref Id 10) When we go back with our daughter, many people come to see. So we will tell them that if your child has any eye problem, you should go to the nearest eye doctor. (ref Id 16) Parents should bring the children here for consultation. Yes the camps should be organized frequently … so that other children should not suffer what my children suffered. Whatever has happened with my children should not happen to others. (ref Id 20) Yes we will go and inform the villagers. Actually this is how it happens in the villages. Whoever knows, has to give proper suggestions or accompany to come here. (ref Id 20) Now that I have come to know about this eye hospital, in future, if I come across any such child, I will eagerly suggest them to come here and accompany them as well. (ref Id 4)
	Stability of intention	2	P (1), M(1)	I don't know about other things. But it is very important eyes to have regular check-ups, drops etc. We come here once in two months. But in between also if we notice even slight difference or abnormality we get in touch with Sir over phone/WhatsApp and follow his suggestions. If required, we even pay a visit. (ref Id 18) Among our relations and neighbourhood too there is no difference. The boys and girls are treated equally. The place where we stay is very good. No one discriminates. (ref Id 20)
	Commitment/ Motivation	2	P (1), M(1)	90% of the responsibility lies with us as parents, we have to take the responsibility and take the child to the doctor in time and take the treatment and follow the instructions of the doctor. (ref Id 2) The pain… And the medicines which need to be applied at regular intervals. These are the risks and challenges. Obviously the benefit is good vision. (ref Id 22)
	Routine	1	M (1)	Parents should notice if the children have any difficulty in reading. If the child is keeping the book too close while reading. If the child is having any problem in reading they should immediately take him to the hospital. (ref Id 23)

Nature of behaviour	Direct experience	4	P (2), F (1), GP (1)	I know in this hospital we can get free treatment so, I came here. (ref Id 1) Our older people keep on coming here. So, I got the information. No, our elders... his grandfather has come here. (ref Id 13) Never we will get arrange marriage for our children within the relatives. Now that we know … We did because we didn't know. (ref Id 18)
	Breaking habit	1	F (1)	At home they were saying to put something or other …it might work … desi [indigenous] medicines …No, they told me to go and get it. But there was no guarantee. So I said what the use is if it doesn't work. So I didn't use any. (ref Id 15)
	Automatic behaviour	1	GP (1)	In our country during the time of birth itself it should be done once by the doctor in the hospital. (ref Id 29)

Behaviour regulation	Action planning	2	P (2)	Meetings can be arranged in the village to discuss these issues. The meetings could be arranged through the village head or can be conducted in the village primary school where all the parents should be called. These things should be discussed in that meeting. If people are told in such meetings, many people will be aware. (ref Id 10) We can also conduct awareness programs during the fairs. Health exhibitions can be conducted and such knowledge could be given. (ref Id 10)
	Generating alternatives	12	P (4), F (6), GP (1), M (1)	In the villages eye camps are held for older people. Doctors come there. They identify the cataracts and take them for surgery. The camp is held once in a year. But they do not check the children. Nobody knows or understands…. Yes it would be very good to check the children in the camps. No need to go here and there. (ref Id 11) You can make these pamphlets. So we will send it to other villages. Information has to be given everywhere. (ref Id 13) Yes, some people don't know that even small children could get cataract. Now in our village everyone has come to know. This should be publicized. Now that we know this, we have to tell in our village. Those who are going to other villages should tell the same … That the small children could have problem. Get them checked. People will come to know …. Also if it comes on TV or newspaper it would be useful. (ref Id 14) I think if it comes in the newspaper many people will come to know. I can tell in my own village. But there are other villages far away …(ref Id 14) So your publicity will happen through us. We go back and tell people that the doctors at this hospital are good, it has the best facilities. (ref Id 16) Those who don't have awareness can ask others. They can ask their friends, relatives, customers … if she/he has any information, she/he will share it and based on that information we can meet the doctor. (ref Id 19)

	Facilitators	2	F (2)	For coming directly some kind of link is required …where to go, what to talk…? Say if had come alone, I would have been confused… what to do, where to go … So when I came here through camp, I had a slip with me where it was written 'contact counter no 4'. So I went to the counter no 4 where the registration was done and then whatever was required these people went ahead with their work and prepared the file. (ref Id 5) In general hospitals it happens like – go to counter number 3 or go to counter number 4 … and the person goes around in circles. But here you don't have to do anything. Even the file is also carried by a person. He will make you sit down. After you are seen, the file goes to another place… (ref Id 6)
Knowledge	Knowledge about condition	7	P (3), F (1), GP (2), M (1)	Yes, white colour patch in the eyes is called cataract… only operation is the treatment for cataract (ref Id 1) There was this white coloured thing in his eyes… like a film. So, I could understand that it could be cataract. Got him examined and was confirmed that it was cataract. (ref Id 14) It's not a good idea to delay the surgery. I feel the eye will get weaker if the surgery is delayed. It is better to get operated at the right time for a better vision. (ref Id 22) For cataract in children, surgery is the only option, it will not be cured by spectacles and medicines. (ref Id 23) Yes I knew… It could happen in any age. Some get it in the old age, some get it young. Some have it from birth. The white spots start coming in the eyes. (ref Id 7)
	Procedural knowledge	5	P (3), M (2)	I know that after operation lens is given and the vision comes back. It gets cured. (ref Id 10) Now we have to implant the lens and this is the first step of the treatment and we need to go forward. Doctor will tell us what needs to be done in the future. (ref Id 2) We would provide her with sun-glasses and clean her eyes with clean soft cotton for hygiene. (ref Id 22)

	Related Knowledge	7	P (3), F (1), GP (2), M (1)	Spinach, carrot, papaya are good for the eyes. They prevent night blindness. We also tell the pregnant mothers to eat nutritious food like milk, curd, rice, and pulses etc. which are available normally at home. (ref Id 10) Fruits like carrot, papaya, spinach and other vegetables… dry fruits…milk… since the time they have started eating, we give them all of these. I know that these are good for the eyes. (ref Id 18) Yes, I feed them eggs, vegetables and yellow fruits. I have studied up to ten years of school education. I read in the books. (ref Id 23) I have heard that we should eat green vegetables and carrots…these things keep the vision good in eyes. (ref Id 6)
	Knowledge on sign and symptoms	13	P (1), F (6), GP (2), M (3), FG (1)	She would look only downwards, never upwards. I would say there must be some reason that she never looks upwards... (ref Id 10) He would see less. I mean …. Weakness ……he would see whatever is near. If you tell him to bring something, he would search for it. (ref Id 15) When he used to go out in the sun, he would close his eyes with his hands. (ref Id 19) Whenever we talk to the baby she looks around not facing me at the time baby was 4.5 months old... (ref Id 2) He ….always squeezes his eyes... when he goes out in the sunlight. (ref Id 24) Unable to see and the black area in the eyes would always 'dance'. The child would frequently close the eyes. (ref Id 5) She had trouble in seeing. She used to see like this bending her head on one side and squeeze her eyes always. (ref Id 6) He can't see … there is a curtain like thing. You throw something … he searches for it …. He cannot see it. (ref Id 7) Children cannot identify the problems. We only have to see. If they are holding things properly. If not then we should understand that the child has problem and should take him to the doctor. (ref Id 7)

	Awareness about the facility	2	P (1), F (1)	For three four years I know about the hospital … The villagers know about it. They told to come here. So I was coming by myself… not through the camp. (ref Id 15) We searched on google. For the best doctor for cataract surgery. Thus we came to know about this Hospital. (ref Id 22)
	New knowledge	6	P (2), F (3), GP (1)	Even younger children … 2 months or even 2 days old children can have eye surgery…the doctor told us. (ref Id 18) We didn't hear about it occurring to new born babies. Then we searched it on the internet and came to know that it happens to new born babies too. (ref Id 29) No, I haven't seen. Here I have met many people whose children have cataract. Even 2-3 months old children have cataract I came to know. (ref Id 3) I don't have knowledge about this. But I have seen here that very small children are operated upon. I have seen children as small as one-year-old.(ref Id 6)
Beliefs about capabilities	Optimism	2	P (1), M (1)	Here we have no problem at the hospital (ref Id 10) I bring her here for check-up and tests. All four of my children come here for check-ups… (ref Id 20)

	Perceived competence of the doctor	20	P (5), F (11), M (4)	The doctor examined them on our first visit and assured that there is nothing to worry. There are various reasons for this. But it can be solved up to some extent through proper treatment. He also assured that if we follow what is suggested then there is maximum chance that they will be fine. We have no idea about how cataract is managed… If we are consulting with the doctor, we have to believe on him. (ref Id 18) Whatever the doctor advise we have to do, doctors have the Jawabdhari [responsibility] so we need to follow their advice. (ref Id 2) We have to act according to doctors' advice and it's our duty to take care of the child. (ref Id 2) No, we didn't have any idea about when the child has to have eye surgery. Whatever the doctor suggests we would do that. This is the general thinking. Whatever the doctor says, people follow that. (ref Id 3) The doctors told that the surgery should be done immediately as with time the situation of the child would worsen. They showed me children aged as little as 4 months on whom surgery had been done and tried to convince me. They said that it is quite normal. After knowing all this, I became confident and went ahead with the surgery. (ref Id 4) We are not much familiar with the hospitals. We prefer to go to the private hospital where the cost would be higher but treatment is better. For better treatment we can even decide to sell our land. (ref Id 4) Now see my son is three and half years old. I got his surgery done. It is up to the doctor … he has to tell if it could be postponed … No it is not up to me … we can't force …. It is up to the doctor to do or not to do. He will tell after how many days he would operate. (ref Id 7) I did not know about this [cataract]. They told in the school, I was not there. No I was not scared. I thought that the doctors are there. So why should I fear. (ref Id 8)

9.6.2 Complete Barriers results, sorted by TDF Domain

(P – Parents; M – Mother; F – Father; GP – Grandparents; FG –Family group)

TDF Domain	**Identified Theme**	**Frequency (*n* transcripts)**	**Interviewees (Roles, *n*)**	**Sample Quotes**
Beliefs about consequences	Outcome Expectancies	**3**	P, GP, FG	It is good to go for surgery if he is cured. Surgery should do good … but they said that the white spots won't go in his eyes. So why to go for the surgery …. That's why I didn't go again (ref Id 27) Risks were there… we were worried that the doctor was taking more time for our child. Other children were coming out after surgery in lesser time. Then the doctor had blood stains in his hands… She was crying that what would have happened to the baby. He was in empty stomach since the morning. (ref Id 29) Now that she does not have the eye which she originally had during her birth, my concern is that she should not have any problem after 5-10 years. She is a small girl. There should not be any issue when she grows up. (ref Id 3)

	Attitudes	10	P (4), F (3), M (2), WF(1)	No…. we never thought the child should go for an eye check-up when there is no problem... Only if there is a problem, children should be taken for check-up. Otherwise not necessary. (Ref ID 10) Only when there is problem in the child we will go to the doctor. If the problem is not visible, we will wait till the problem is visible and if any one identifies it we will go to the eye doctor only. (Ref Id 2) I have told my wife to take care of our child. She only has to cook and no other work...remain at home… Nothing else. I am working. That is enough....and, she never worked. Sometimes children do mistakes … but mother has to look after them to protect them from any eye injuries... (Ref Id 11) We are village folk. If the child does not have any problem, we don't do anything. Only if the child has a problem we take him to the doctor. We don't have any eye doctor nearby our house… (Ref Id 3)

	Beliefs	16	P (1), F (11), M (1) GF (2), GP (1)	It is about the faith in god… if god can cure, let him cure… no need to worry (Ref Id 13) Baba [local priest] gave him some medicine and suggested to put it on the eye lashes… so that the cataract will get cured. We did for 2-3 months and it didn't work. (Ref Id 13) People do practice… if dust falls into the eyes, they put oil in the night. But nothing much about children. It has happened to me during my schools and college days. Something has fallen into the eyes. So, put oil and sleep. Or else put sandalwood paste around the eyes. Thus the eyes would water. (ref Id 18) We were also told that if early morning saliva is applied in the eyes it will be cured. But since he had it from birth … We didn't do anything. (ref Id 29) I noticed his movements and asked my parents about it – why he walks like that … he would look as if he has crossed eyes. My parents said that your child has crossed eyes that's why he walks like that. They said that it is a good sign of luck (ref Id 4) From his birth he had a white spot in the eyes. We noticed within one to two weeks of birth. He was delivered in a hospital and both I and his mother noticed it. I came to know that this is cataract. But I didn't think of doing anything because since he had it from birth it was a curse of God and nothing could be done about it. (ref Id 31)

	Critical incidents	5	P (1), F (3), WF (1)	She had problem since beginning. She had trouble in seeing. She used to see like this bending her head on one side and squeeze her eyes always. Then we showed her to a local eye doctor. He did not say anything. He only gave number for spectacles. But her discomfort continued. After that we showed her to another doctor who gave medicines to eat… We did all this in our area, where we live. Our local doctor...It is within Delhi… (ref Id 6) A few children were playing. One child was having an iron rod in his hand. Then he beat my child while playing and accidently it hit in the eyes of my child…(Ref ID 11)
	Unrealistic optimism	5	F (2), M (1) WF (1), GP (1)	It happened since he was born. Now he is 4 years old. It is there since four years. We kept on thinking that it will go away, it will be cured. We kept on going to “babaji’s place”. People recommend this place to visit… to get cured. That’s it … and the time kept passing on …(Ref Id 13) No. The baba said that he will cure it. He gives a liquid to drink …there is a baba in the village... he has a single medicine for all problems. Whatever it is …nothing is put into the eyes. (ref Id 27) We didn’t take any chance or do any experiment. We left it to God… let Him do … We should do what should be done. Then it is up to his fate. (ref Id 29)

	Regret	2	P (1), GP (1)	There was no money so he went out for two months and earned money. Then the surgery was done. If we had money, could have done it in the beginning itself when we came. (ref Id 14) Yes… patching exercise needs to be done 3-4 times a day….. We also feel that it was probably a wrong decision to do the surgery early. Had it been later, possibly the lens could have been fitted. (ref Id 29)
	Consequences	19	F (5), M (6) P (4), GP (4)	School was stopped now for some time … yes, he has gone school 2-3 days. He was wearing spectacles. Other children took his spectacles and it broke. Then I stopped sending him again. (ref Id 15) Actually we haven't found the reason yet. When she was pregnant she had everything normal. She was eating well. One reason which I feel could be that I married within relations. My father and grandfather also had married within the relations. I am the third generation that has married within the relations. This could be the reason. Because during pregnancy all check-ups were done and we didn't know that something could happen to the child's eyes. (ref Id 18) If we tell him to bring something, he is unable to pick it up … I felt very sad but he is too small so we didn't go for the surgery. If he rubs the eyes he might hurt himself. (ref Id 26) We are poor people. We somehow fill our stomach through labour work. How would we know? Local Doctor Sahab told that it will take time. So we came back thinking that let him grow up. Then we will do. (ref Id 26)

				We also asked the doctor [with whom we regularly consult for our child] that if my child has any problem in the eyes. He said no there is nothing to worry…Doctor said that new born babies have blurred vision up to 20 days …The child specialist also told the same … Up to 20 days they would have blurred shadowed vision. After that slowly … that's when we noticed. (ref Id 29) Most important is cleanliness. Many are living in a dirty place and it can cause infections in the eyes. (ref Id 22) We always try to give good food to the children. But nowadays children also give trouble. They won't eat. If their mother cooks something, they might not eat. Some would ask for Maggi, some would ask for bread…today vegetable has been prepared but no one had lunch today…Thus we get into a fix and then we have to cook as per their choice. (ref Id 6)

	Not a priority	7	F (1), M (3) WF (1)	She had it even before but our family did not notice it …She was in class VIII. She used to live in the hostel. She informed us that she can't see properly... But we laughed it off … she was so young. How could she see less? Nobody understood. Not even me. When it increased, she told us again after 2 months... Then we showed her to the doctor there. (ref Id 16) Four of my children have got cataract. I didn't understand during my first child. She was fine until the age of five years. Afterwards she started having crossed eyes. She would see diagonally. Everyone at home would laugh… What kind of disease is this … She got habituated like that … Then later we consulted the doctor. (ref Id 20) Nobody goes to Anganwadi [government run nutrition centres] centre. Only Daliya [(mixed cereals for hotchpotch] is available ... The animals are fed… it is not given to the children. Only animals eat those cereals …(ref Id 27)

	Perceived risk/ threat	6	F (2), M (3) P (1)	Yes. We could notice in 3 - 4 months of age. I was afraid of surgery that he is small … Some people would say that his eyes would get squashed … this …that … Will take the lenses out ... So I was afraid. At 5 years I showed him in hospital. (ref ID 20) “The lens will break. That’s why we didn’t do it out of fear. We thought that once he grows up we will do it. We are afraid that the lens might break. (ref ID 26) He was identified with cataract… He used to see a little diagonally. So I took him to the private doctor. He said that there is cataract in the eyes. This was two years back from now. He suggested surgery. I got afraid. One of my sons … he is 22-23 now … at that time he was about 10-12 years old …he was operated for cataract but it was unsuccessful… So I started fearing. If surgery is done and my second son would also loses his sight. (ref ID 23)
	Review	1	M (1)	In the government hospital only the doctor’s consultation is free. You have to pay for the medicine. I could arrange some money in three years. Then I went to the hospital. We visited four times. Then they did the surgery. The surgery was done for the nerves. We visited one month after the surgery for follow up. Even after surgery she can't see properly in the operated eye. They called for the next surgery. But we didn’t go… (ref ID 30)

Environmental context and resources	Economic	33	F (13), M (12) P (7), GP (1)	Yes madam. I do labour job. It is labour job. If you go, you get (wages), if you don't go, you don't get... (ref ID 16) Although the surgery was free at government hospital, the transportation cost is high. We couldn't arrange it for the second time. It costs about 100 rupees per head. But we earn less than 100 rupees (ref ID 30) It took months to recognise the problem in my child. We took the child to the general hospital they asked huge money for the surgery as we don't have good financial condition, we couldn't do. We had only yellow ration card which is eligible for only some concession. (ref ID 2) It was harvesting season. That work had to be stopped. We were supposed to work for some other people on contract. That was also stopped. We had to come here yesterday… We had to borrow the required money for the surgery. We are poor people. We had to request for the money from relatives. (ref ID 3) People also think that if we go today, the whole day will go and the day's earning will be lost. So our routine will be disturbed…. This is also a reason. (ref ID 6) It would take about 4-5 years to arrange the money, Rupees five thousand. Even though the surgery is free, they asked us to pay INR 2700 for giving injection by a special doctor for pain less (anaesthesia). (ref ID 30) She will go to someone else's house. She is not mine. Now tell me where would I get her married? Our days are over…. If we don't do for the girl, who will do for her. No one will do. We don't want to sit with the problem. But we are helpless because of money. What to do …(ref ID 8)

	Health care facility	21	F (10), M (8) P (1), GP (2)	A week after the operation he was called for checking. On being checked they said there is some problem and we don't have facility to treat this and suggested to take the child to this hospital. When we reached here after checking the doctor gave medicines for 15 days and said the surgery that was done earlier is still not healed. So he will be able to operate after 15 days. So I Came after 15 days to this hospital for surgery. (ref ID 11) There is no eye hospital near by us, but the local hospital referred us immediately to this eye hospital. The doctors are not well trained at the local hospital also there is no machinery to operate on the child so they sent us here. It will be better if any eye hospital available in our area. (ref ID 2) There is a general doctor available at the local primary health centre. There is no eye doctor. For any eye doctor we need to travel 40 kms to the main town. (ref ID 30) For eye problems people go to the doctors in nearby town. They would give medicines and a pair of spectacles with which one has to be happy. Other than that there is no surgery service available close by. (ref ID 4) Till date we never had any eye camp in our villages. We have to depend on these village doctors. We don't have other options. (ref ID 4) If we go to the government hospital, they say go to that place with this slip, or go to that doctor… if someone goes to the hospital, for one report nobody knows how many hours or days it will take...(ref ID 5) For coming directly to the hospital some kind of link is required … where to go, what to talk…? Say if had come alone, I would have been confused… what to do, where to go … I will be lost in this big hospital(ref ID 5)

	Environmental stressors - Mobility/ transport	5	F (1), M (2) P (2)	Because its hilly region not much transport, only there are smaller shared vehicles. It costs 100 rupees up & down. Another 10-15 rupees to go to the government hospital. (ref ID 30) We live in a village. So we have to come and stay in an acquaintance's place in the city. We have to start around 4 am in the morning to catch the bus. Then we have to wait for the train… When the train comes … sometimes we miss the train, so we have to wait longer …This time it was very difficult. We were waiting for the bus in the darkness, fog on the roadside … with the child …. The child also caught cold... (ref ID 10) No difficulties except that coming by train becomes a bit difficult at times…. From that far. We have to come in the general compartment. Sometimes it is crowded, sometimes it is comfortable…(ref ID 14)
	Environmental stressors – Distance	3	F (2), M (1) P (2)	We paid Rs.115 for train fare per person and travelled around 225 kms. (ref ID 16) Yes, it is too far… It takes four hours from Mahbuba to here… Another three hours from Khajuraho. Yes, and it is another 12 kms by vehicle from Khajuraho. (ref ID 13)
	Environmental stressors – Time	3	F (2), WF (1)	If there is no problem, who would go for check-up. Who has so much time nowadays…..Only when there is a problem people are ready to go anywhere. (ref ID 28) Everyone knows you don't have to spend money at this hospital. Another thing is that people think about the time. They think that more time will be spent, the whole day will go. Mostly they go to the local doctor, get a drop prescribed, and take medicines. Mostly this happens. (ref ID 6)

	Nature of Environment	2	F (1), P (1)	If we take care of the cleanliness only then my child will be fine. If we remain busy with our own work, and do not care about what the child is doing and where he is going then definitely bad things will happen. Anything can happen. (ref ID 5) Most important is cleanliness. Many are living in a dirty place and it can cause infections in the eyes. (ref ID 22)
	Person X environment interaction	8	F (5), M (1) P (2)	Many in my class [a child with cataract] tease me calling me 'blind'. (ref ID 30) We do not take much care about our children's eyes. When they watch TV we don't care about what the distance should be, we don't care about how much time the children should watch TV, we are not careful about the food that children should eat so that their eyesight should not be weak. (ref ID 6) After going from here he told that he wants to go to school. I told to wait for a few days … you never know …. While playing with other children he might get hit. He went one day. He was wearing spectacles. Other children took his spectacles and it broke. Then I stopped sending him again. (ref ID 15)
	Alternative medicine and Traditional practices	3	F (1), WF (2)	They just said that he got injured in the eye. There were white spots in the eyes. It has reduced. For the last one month I have stopped the drop and continuing with the 'desi' (indigenous) treatment in the village. It's a jari (herb) I don't know… there is one 'baba'. He gives... (ref ID 27) They said surgery has to be done. I thought it would be cured by homeopathy and treated for 3-4 months... (ref ID 28) For minor condition we do not have an option other than to go to the village doctor. Only when something goes wrong, people become cautious and avoid going to village doctor. (ref ID 4)

Social influences	Social support (lack of concern/ misguidance/ inappropriate advice etc.)	7	F (3), M (3) P (1)	I [a child with cataract] can't see the board clearly. I try to read the words one by one. Many in my class tease me calling me 'blind'. (ref ID 30) I noticed his movements and asked my parents about it – why he walks like that … he would look as if he has crossed eyes. My parents said that your child has crossed eyes that's why he walks like that. They said that it is a good sign of luck (ref ID 4) In between I was a little scared, people scared us that something or other would happen. (ref ID 6)
	Social identity	3	P (3)	No, nothing special. We are a middle class family. We feed the children the normal food which is prepared at home. (ref ID 10) There are people who think like that … even nowadays in my area. Boys receives better care than the girls. (ref ID 18)

	Social pressure	8	F (2), M (3) P (2), WF (1)	My daughter would look always downwards, never upwards. I would say there must be some reason that she never looks upwards. But elders at home and many people said that this happens to the children and it will be cured later. (ref ID 10) It happened since he was born. Now he is 4 years old. It is there since four years. We kept on thinking that it will go away, it will be cured. We kept on going to “babaji’s place” [local priest]. People recommend this place …… all problem gets cured… Yes, people were telling that it will get cured if visit to babji’s place... (we were) thinking … Good if it gets cured…(ref ID 13) Yeah, people said about Ayurveda treatment. We had tried with Ayurveda in parallel and came to know that by applying Ayurveda medicines in the eyes cataract could be cleared. When we came for the surgery we received calls suggesting us to not to go for the surgery… (ref ID 18). At home they were saying to put something or other … it might work … desi medicines …No, they told me to go and get it. But there was no guarantee. So I said what the use if it doesn’t work. Someone gives … Some local Ayurveda doctor … Yes “jari-buti” (herbs) … and suggested it takes some time to get cured…(ref ID 15).

	Power / hierarchy	7	F (3), M (2) P (1), WF (1)	I have told my wife to take care. She only has to cook and no other work. Remain at home. Nothing else. I am working. That is enough... she never worked. Sometimes children do mistakes … but mother has to look after them to protect them from injuries... (ref ID 11) When he would drink milk, I noticed white spots in the eyes. I told to my mother in law. She said it happens in children. I said no but she was the head (in the family)… and she didn't agree. (ref ID 14) I have accumulated the money for his operation … Six thousand rupees. But my in laws were not allowing us to go for surgery as everyone feels the child is too young... (ref ID 26) People in the family are saying that he is too young, his eye might get spoiled... My father also said … my father supports the family with his earnings. So I have to listen to him. (ref ID 27) I only decide always. How would my wife decide…? We men only have to do the outdoor works. How would the wife know where to go, what to buy, where the medicine is available… I only have to bring all the things. (ref ID 7)

	Social norms / culture	13	F (5), GP (1) P (6), WF (1)	We felt very sad. She is so young and she has got cataract! What would happen if we get her married? Problems can arise in her marriage life. (ref ID 16) One reason which I feel could be that I married within relations. My father and grandfather also had married within the relations. I am the third generation that has married within the relations. This could be the reason... (ref ID 18) We were having festival time. As soon as the festival was over after 10 days we came here. (ref ID 29) We are village folk. If the child does not have any problem, we don't do anything. Only if the child has a problem we take him to the doctor (ref ID 3) Among people who are not educated there is a difference in how they treat boys and girls but it's the same among the educated families. (ref ID 22)

	Parental negligence	6	F (3), GP (1) M (2)	As a grandparent, I take the decision because the parents are upset because the child has got this problem and they are not willing to spend on them… (ref ID 1) She has the problem from May-June. She had it even before but our family did not notice it – what was there in her eyes. She was in class VIII. She used to live in the hostel. She told also. But we laughed it off …… she was so young. How could she see less? Nobody understood. Not even me. (ref ID 16) Whenever we advise the parents with the children with cataract or squint they refused to go to the eye hospital and they said it will cure on its own. So we don't force them. (ref ID 2) In our area, mostly whatever is done, is done by the ladies. Our area people are mostly labourers. Men go to work. Ladies remain at home. They take the children to the doctor, they drop them to school, pick them up. Mostly these works are done by ladies. They do not care much. If children have a little problem, they ignore it. (ref ID 6)
	Organisation norms	2	F (1), M (1)	I always listen carefully to any announcement that is made in our area. So that if there is a camp I can take my children for check-up. But the camp was organised only after four years (ref ID 20) Till date we never had any eye camp in our villages. We have to depend on these village doctors. We don't have other options. (ref ID 4)

	Conflicts	2	F (1), M (1)	He suffered injury and was operated… got hit by ball while playing. About twelve years back. After operation he could see for a few days, then he stopped seeing. Then I took him to the hospital. Doctors were not available due to strike. In this confusion he lost his vision slowly. (ref ID 23) Yes, we have given all immunisation to him. The nurse didn't say anything about his eye problems. He is eight years now and he does not go to school. He used to go. But due to this problem he could not see and stopped going. (ref ID 31)
Motivation and goals	Certainty of intention	11	F (4), P (4) M (3)	But if there is no problem, the village people do not bother about it. Yes, if there is any difficulty we go to the doctor. If there is no difficulty, then why to go? (ref ID 14) If hospital facilities were available, even girls would also get treatment. Otherwise … Curse of God …(ref ID 31) First thing… I did not want my child to be operated upon as he is too small. If something happens … I had never before known or seen such a small child being operated. That's why I never thought of getting the surgery done. (ref ID 4)
	Priority	7	F (3), P (2) M (1), GP (1)	Care should be taken about the children. Parents should be careful. They should be present while children are playing. (ref ID 10) They told to come after 2 months... we have to see ... there is no time, expenses too and we have to close the shop... it gets more difficult for other two daughters to go to school (ref ID 12) Hospital do a lot of follow up. Now, the parents should also understand that it is their responsibility and is beneficial for them to follow what is advised as a priority. (ref ID 19)

	Intention	6	F (3), M (1), WF (2)	I thought it would be cured by homeopathy and treated for 3-4 months. (ref ID 28) They said lens would be fitted. But they also said that the white spots won't go even after the lens is fitted inside. So I didn't go there again. (ref ID 27) People also think that if we go today, the whole day will go and the day's earning will be lost. So our routine will be disturbed…. This is also a reason. (ref ID 6) There are still some people who think even now ... Mostly among those who are uneducated. You can see in the villages …. What can I say … Due to such problem they can't even do the surgery. Children lose their sight. Because of not doing the surgery. (ref ID 19)
	Goals and motivation	3	P (1), M (1), GP (1)	Two times camp was organized. I got two of my children treated through the camp. I didn't go to hospital directly as I had no money.(ref ID 20) As a grandparent, I take the decision because the parents are upset because the child has got this problem and they are not willing to spend on them. (ref ID 1)
Emotions	Effect	8	F (3), M (3), GP (2)	He went one day to school after surgery. He was wearing spectacles. Other children took his spectacles and it broke. Then I stopped sending him to school again. (ref ID 15) My husband takes alcohol every day and he spends around RS 40 - 50 per day on this. he fights with me every day, shouts, beats up and abuses me… he doesn't care about the child as well (ref ID 30) I don't feel good that a lens could not be fitted. Doctor has suggested exercise. But he [the child] doesn't let us to get him to do those…as he is unable to see with one eye at all. The doctor didn't tell us about it earlier the lens couldn't be fitted … we don't know what the problem in putting the lens… now he needs to use contact lens permanently. Until now he must have lost 10-15 lenses (ref ID 29)

	Stress	8	F (5), M (2), P (1)	What can I say … How I felt in my mind … It caused me problem … I don't stay at home … I live away. I was called …I had to come overnight. When I went home, I came to know that he was not there. He was admitted here so I came here directly. I am not at home for the last two months. I have come here and I will go back from here itself. Too much difficulty… (ref ID 11) His father is doing labour job … Here we have difficulty in getting food and now all this … you should understand. There is no rain, only dry taps. No water. (ref ID 26) My husband never takes any responsibility for the child and home. He lives in his own world and he needs only money for his drinking... (ref ID 30)

	Anxiety/ Depression	8	F (1), M (3), P (3), GP (1)	I felt very bad. I cried a lot for two-three days. Such a small child, what has happened to her eyes, how we would manage … we thought all these and cried. (ref ID 10) At the hospital where the doctor said that he has cataract. This was first time for us as no one in our family earlier has any such problem. The thing which should occur after 45 years of age had happened in such a small child … my family was shattered. Moreover, we had twins. So both the children had in both eyes. (ref ID 18) We were worried that the doctor was taking more time for our child. Other children were coming out after surgery in lesser time. Child's mother was crying that what would have happened to the baby. He was in empty stomach since the morning. (ref ID 29) My second daughter's vision is very weak. She can't even see you…sitting so close…respondent cries... (ref ID 20)
	Fear	5	F (2), M (2), P (1)	"The lens will break. That's why we didn't do it out of fear. We thought that once he grows up we will do it. We are afraid that the lens might break. (ref ID 26) I felt very scared about surgery… Because she is very young …(ref ID 12) We could notice in 3 - 4 months. I was afraid of surgery that he is small … some people would say that his eyes would get squashed … this …that … Will take the lenses … so I was afraid. At 5 years I showed him in hospital. (ref ID 20)

	Anticipated regret	4	F (1), M (1), P (1), WF (1)	We felt very sad. She is so young and she has got cataract! What would happen if we get her married? Problems can arise. (ref ID 16) Whenever we advise the parents with the children with cataract or squint they refused to go to the eye hospital and they said it will cure on its own. So we don't force them. They won't realise this now when the child becomes big they will realise the problem. (ref ID 2) I didn't realise so far…If he cannot see then I must get him treated. Otherwise when he grows up he will blame us that we spoiled his eye. (ref ID 27)
	Burnout	2	M (1), P (1)	Coming by train becomes a bit difficult at times…. From that far. We have to come in the general compartment. Sometimes it is crowded, sometimes it is comfortable… Money … well … we are poor anyway … we have to arrange for money by doing labour work …There was no money so he went out for two months and earned money. (ref ID 14) There are no problems at this hospital but we faced problem in coming here. We started at 8 o' clock from home and we reached at 11.30 at the hospital. It's very far and we had to change three different buses. Till we reach back our home, I became very tired and exhausted. (ref ID 2)

Skills	Competence of local doctor/ nurse/ school eye health team	4	F (3), GP (1)	We also asked the doctor with whom we regularly consult for him whether he has any problem in the eyes. He said no there is nothing to worry. No. They say that new born babies have blurred vision up to 20 days …..(ref ID 29) Yes, we have given all immunisation to him. The nurse didn't say anything about his eye problems. (ref ID 31) He goes to school but no one clearly said anything about his problem. In the school eye screening they checked several times in the school and said that there will be a camp organised soon and the doctor will come to the camp and needs to be examined by the doctor only. (ref ID 5)
Social professional role and identity	Organisation role	2	M (1), F (1)	For my third child, I came through the camp and came to the hospital with their prescription. They said surgery was required. I said ok. Then I enquired about the younger child at the hospital who also had cataract… I asked madam about the expenses. She said minimum twenty-five thousand. So I had to sit back because I cannot arrange so much money. Now again the camp has been organized after four years. I showed him there. (ref ID 20) Camps are organized in our area. But these are done once in two months or six months or one year (no regularity). The second thing is, in these camps they don't talk about children's problems. Mostly the elderly people queue up and they do not pay attention to the children. (ref ID 6)

Behaviour regulation	Barriers to Goal	3	GP (1), F (2)	Only the patching exercise … I am unable to get him to do exercise … I am afraid that he might cry(ref ID 29) Now that surgery is suggested, then if spectacles are required after surgery…. The child can't wear spectacles or will not be able to protect it. So it will be better to do the surgery after 5-6 years. (ref ID 5) In the school eye screening they checked several times in the school and said that there will be a camp organised soon and the doctor will come to the camp and needs to be examined by the doctor only. He goes to school but no one clearly said anything about his problem, so we waited for the camp (ref ID 5)

Beliefs about capabilities	Perceived competence	8	F (4), M (1), P (1), GP (2)	There is no eye hospital near by us, but the local hospital referred us immediately to this eye hospital. The doctors are not well trained at the local hospital also there is no machinery to operate on the child so they sent us here. (ref ID 2) She used to squeeze her eyes…… roughly at the age of three years. We thought it's not normal so We searched for a hospital….Just for the normal eye check-up …. We went to the nearest eye specialist and We went in the same week. They could not detect the cataract. They just gave spectacle prescription. We doubted and went to other hospitals ….(ref ID 22) She had problem since beginning. She had trouble in seeing. She used to see like this bending her head on one side and squeeze her eyes always. Then we showed her some doctor. He did not say anything. He only gave number for spectacles. But her discomfort continued. After that we showed her to another doctor who gave medicines to eat. We did all this in our area, where we live. Our local doctor...It is within Delhi…Yes -yes, eye doctor. He checked and gave number... (ref ID 6) We did not think that she has this kind of a problem. Yes we thought it was a simple problem. We consulted the doctors, her vision was weak, and so we gave her spectacles … This was in our minds. We did not think that she had cataract which needs surgery. (ref ID 6)

	Perceived competence on government hospital	2	F (1), M (1)	In the government hospital only the doctor's consultation is free. You have to pay for the medicine. I could arrange some money in three years. Then I went to the hospital. We visited four times. Then they did the surgery. The surgery was done for the nerves. We visited one month after the surgery for follow up. Even after surgery she can't see properly in the operated eye. They called for the next surgery. But we didn't go ... (ref ID 30) We go to the government hospital, they say go to that place with this slip, or go to that doctor. And in our place if someone goes to the hospital, for one report nobody knows how many hours or days it will take. (ref ID 5)
	Optimism	1	P (1)	People said about Ayurveda [other form of medicine based on plants and herbs] treatment. We had tried with Ayurveda in parallel and came to know that by applying Ayurveda medicines in the eyes cataract could be cleared... (ref ID 18)

Nature of behaviour	Direct experience	6	F (3), M (2), WF (1)	We brought him once when he was even younger. He had cough. We were told that surgery cannot be done. So I thought, surgery cannot be done in very small children. (ref Id 13) He was identified with cataract… He used to see a little diagonally. So I took him to the private doctor. He said that there is cataract in the eyes. This was two years back from now. He suggested surgery. I got afraid. One of my sons … He is 22-23 now … at that time he was about 10-12 years old …he was operated but it was unsuccessful… So I started fearing. If surgery is done and he also will lose his sight. (ref Id 23) In the government hospital only the doctor's consultation is free. You have to pay for the medicine. Then I went to the hospital. We visited four times. Then they did the surgery. The surgery was done for the nerves. We visited one month after the surgery for follow up. Even after surgery she can't see properly in the operated eye. (ref Id 30)
	Past behaviour	1	F (1)	Yes, there are these small capsules... We used to put those if there is redness or dust falls in the eyes. (ref Id 16)
	Routine habit	2	WF (28), F (1)	He keeps roaming around the house and neighbourhood whole day. There is no problem as such. He doesn't require much attention. Eats, plays, doesn't trouble much. If he is hungry he would ask for food. He would go to the toilet when required. No difficulty. (ref Id 28) For weakness etc. we take medicine from the medical shops. If there is fever, we go to the nearby hospital. (ref Id 31)
	Breaking habit	1	F (1)	We always try to give healthy food to the children. But nowadays children also give trouble. They won't eat. If their mother cooks something, they might not eat. Some would ask for Maggi, some would ask for bread. (ref Id 6)

Knowledge	Knowledge about condition	19	F (9), M (5), P (4), WF (1)	Yes, I have heard about cataract before. Often older people get cataract surgery. So I knew about cataract. But, I never heard or saw cataract in children. (ref Id 10) Yes, I knew that cataract happens to older people. Didn't know that even our baby would have it. I used to notice white spots in both her eyes. I used to tell others in the house. They would say that it might happen to the child. It will be okay. (ref Id 10) We didn't know about cataract. Now see some people have brown eyes. We used to think that they have white eyes. We didn't know that they had cataract. We came to know about it later. (ref Id 20) From his birth he had a white spot in the eyes. We noticed within one to two weeks of birth. He was delivered in a hospital and both I and his mother noticed it. I came to know that this is cataract. But I didn't think of doing anything because since he had it from birth it was a curse of God and nothing could be done about it. (ref Id 31) No. I have no idea about cataract. (ref Id 31) Operation for eye injury was done but then slowly this whiteness arrived. I haven't heard that cataract occur after an eye injury. (ref Id 11)
	Knowledge	5	F (4), P (1)	In the villages, many people don't know that children having eye problems should be taken to the hospital. There is no information. (ref Id 16) I don't have an idea. In our place, we don't prepare food separately. Whatever is prepared, will be consumed by the mother, father and the child…… the same food. (ref Id 5) No there is no such food. We eat only normal food. I don't have any idea. (ref Id 7)

9.6.3 TDF domains, Themes and the quotations coded from the focus group discussion

TDF domain	Themes	Example excerpts from the discussion
Knowledge	Knowledge about childhood cataract and its causes	'When the mother consumed alcohol or smoked during pregnancy, there is a chance for the child to be born with cataract'. (VT) No… we never heard about rubella. Heard the name rubella…not very clear about it…I have heard that it affects children but not sure what it is… There is no clarity on this… (VT) I learnt that the child gets cataract if the mother does not eat healthy food during the pregnancy... (VT) When the child's eye gets injured during the play... it can also lead to cataract…(VT) I heard that premature babies will also get cataract... (VT) In adults, cataract forms when they use more steroids for any other treatment similarly even in children if they used medicines like steroids they can get cataract early... (VT) Some cataracts are treatable and some are not. If there are any retina problems then it becomes difficult to completely treat. If it's only cataract with surgery it can be treated. (VT) Cataract in children is less in the villages but there are many children with retinal problems…(CECW) If there was any issue during delivery it can affect the child. Also consanguineous marriage can affect the child…(CECW) Vitamin deficiency will also cause cataract in children they need to give vitamin A drops to the children otherwise it can affect the child with various eye problems…So mothers need to be counselled for giving children with more vitamin A rich foods to avoid problems. …(CECW)
Skills	Personal experience of seeing a childhood cataract	'I have also seen an 18 year old girl took lots of drugs…. steroids for some other treatment and she developed cataract'. (VT) Last year when I was posted in tertiary hospital for my training, I saw a case… during holy his cousin splashed/ thrown eggs on his face and it hit his eyes and developed cataract. So I realised cataract can come due to any eye injuries and electronic shock… (VT) I have seen a case during my training… a 19 year old girl developed cataract because her father beaten her…and she got operated…(VT) Genetic problems can also cause cataract. I have seen more cases due to consanguineous marriage, there are a few cases in my own family itself. All got married within the relations and my cousin had congenital cataract and Retinitis Pigmentosa when I was young… (VT)

		I have seen a child at the community during a screening program... the child was around 3 years and from birth cataract was present... (VT) We have never seen a cataract in child in our neighbouring villages so far.(CECW) I have seen one child with glaucoma so far in the village. It has occurred due to hereditary, the child's father also had glaucoma in childhood and this baby also diagnosed with glaucoma. (CECW) I have never seen in the community but have seen a 7 year old boy with cataract at the hospital. He had cataract in both eyes and they advised surgery for both eyes. I was shocked to know that children at that age also get cataract. (CECW) We haven't seen in villages but seen a few cases at the hospital during the training program. I have seen babies a few months old with cataract at the hospital. (CECW) I have seen a case with both cataract and glaucoma while undergoing training at the hospital. He was born premature and his eyes got operated for cataract at the hospital. (CECW)
Knowledge	Knowledge on problems faced by children with cataract	They will have distance vision problems. Mostly when they are playing they need to see the objects so they get problem with that and automatically the near vision will also have issues… so vision problems…(VT) Double vision, when they look at any object it will look double and when they look at the light it will look more colourful…no clarity and blurred image ….(VT) Cataract in young child affects growth and can lead to amblyopia as well… can cause retina problems also...as they have to strain more… I feel that their veins will lose its strength...because of that glaucoma can also occur… more chances for glaucoma…(VT) Brain will not function…I mean brain function will be reduced and their attitudes will be affected...they will not be able to understand things quickly… as they can't see things clearly they understand based on what they hear… so the aptitude will not develop stronger and there is a possibility of less IQ development in them…(VT) Children with cataract won't be active like others, as they can't see clearly and depending on others for everything…so they won't be very active…(VT)
Knowledge	Knowledge on prevention	If we stop consanguineous marriage we can prevent all cataract that occurs due to this... We should take care of the children from injuries… to prevent traumatic cataract…(VT) In old people we can't prevent cataract, as the age increases it will definitely occur in individuals. But in children we can prevent them if we avoid consanguineous marriage, blunt eye injuries and if the mother eats good nutritious food…(VT)

		If we create awareness among the rural population about this they will become aware about this…if we discuss among ourselves it will not be known to the rural people, if we explain them, they will take the precautions…(VT) I think if we stop the consanguineous marriage we can prevent cataract in children to some extent say 8 out of 10 cases can be prevented… we need to educate and create awareness about this… When we meet people during school screening or general screening program we have to create this awareness…(VT) We need to educate the pregnant mothers about the nutritious food intake. Through this we can avoid cataract in a few cases…(VT) When kids get injured they go and take drops from medical shops and apply. Which has more steroids drugs rather if they come directly to vision centres we can avoid to certain extent. In general when eye injuries occurs if we reduce the steroids use we can control this to certain extent. (VT) Avoiding consanguineous marriage it not only avoids cataract it protects the baby from many conditions. Also educating pregnant mothers about the nutritious food during pregnancy. We need to advise them to eat proper food…After delivery the new-borns had to be immunised as per the schedule in time and when the child gets into school age taking precautions to avoid eye injuries will help in preventing cataract. Also ensuring eye drops are used as per right prescription. (VT)
Environmental context and resources	Home remedies used for treating eye problems	When a child had red eyes (conjunctivitis) they apply milk…either mother's milk or goat milk…Also when there is any dust fall in the eyes they said they used pin to remove the dust from the eyes… When there is watering or white discharge in eyes… they mixed turmeric in water and applied on the eyes. All these cases have visited to my centre in this last one month... (VT) Some people apply extract from green leaves on the eyes... for redness and watering in the eyes… some people apply neem leaves extract and some apply curd on the eyes…its mostly applied on adults and older people in some cases when the child complaints to their parents about such eye complaints it's been applied on the children eyes as well…(VT) One time a 16 year old complaint having headache and at home they applied dry ginger juice near the eyes and he came to the vision centre with red eyes and his cornea was scarred and caused epithelial defects…(VT) In some old patients they come to the centre applying oil on their eyes and if we enquire they say they applied after prayers from the church thinking this will cure their eye problems…(VT) Applying dry ginger around the eyes for head ache is quite common in the villages. Even when I was a young when I complained of headache my parents applied dry ginger juice around my eyes and it was so irritating the eyes and

		more water from the eyes comes out. It was done with the intention that if there are bad water in the head it will come out. In fact my headache was stopped after this application… (VT) Especially very young children aged 2 months, 3 and 6 months babies, redness, watering and puss formation in the eyes are quite common. For such problems mostly they apply breast milk on the eyes of the babies. They believe that the breast milk will cure the problem…(VT) A few years back even in buses they sell a stick called kalakam it looks like a white chalk piece and it is generally applied around the eyes for any problem in all age group... It causes severe burning in the eyes…(VT) In villages they apply kalakkam for eye problems they mix that in water and apply around the eyes and they believe it will cure many eye problems. For many other problem they apply neem aplicaps bought from medical shops. They do this even for children. This kalakkam they apply it around the eyes showing it to sun and they repeat this for 3 to 4 times in a month…(CECW) I haven't heard any traditional practice for eye problems, but have come across in a few cases applying green leave extract on the eyes for fever and jaundice and lost vision and become blind. A 14 years old boy had this experience and become blind in our village, this was happened 10 years ago…(CECW) Leaves extract for treating eye diseases is not there in the villages now. There is no person in the villages who practices such traditional medicines for eye problems. Generations have changed now so this kind of practice is not found these days…(CECW) But what is quite common these days are without going for eye check-up they buy medicines on their own from medical shop and apply. This practice is quite rampant in the villages now…(CECW)
Skills	Perception about their training	Mostly it's learned during the work. Little information was given during the training about childhood cataract, mostly we gained knowledge when we started working at the vision centre. (VT) I have seen more cases during my practical postings in tertiary centre and also have learned at the vision centre (VT). No I haven't seen any during the training...during my training they said congenital cataract occurs in children mostly in families where consanguineous marriage happens...and surgery is the only treatment... (VT) I heard about retinoblastoma that it occurs in child as soon as they are born…during the training program at the tertiary hospital… but I wasn't sure when the child with retinoblastoma needs to be operated and how do we identify such child in the community which we are working… also would like to know what would be the probable cause for it… only concerns is that if they are not operated on time they will lose their life so I really wish to know more

		on this so that we will be able to identify and help such children in the communities… it will help us to refer the child as quickly as possible to save the life of the child…(CECW) Nowadays more and more kids are wearing spectacles… including my own children… they are taking off their spectacles only when they go to bed otherwise all times they are wearing the spectacles… I feel really pity on them at times and even at my age I can see clearly but my children are not able to see properly… would be interested to know more on why these children gets problem like this and is there a way to avoid such problems…(CECW) We didn't study about eye care earlier before coming to this job… We all started working in the community after training… but, we certainly need to know more on children eye care as its not dealt in detail during our training program… we need to know more about each conditions in children as the parents and communities expects us to answer their questions and also the knowledge on certain conditions will give us enough confidence to convince the parents… it will be good to have separate training session on children eye disease to work effectively in the community…(CECW)
Knowledge	Perception towards children eye examination	Immediately after birth and once in 6 months eye check-up is good for the child. (VT) When the child is 6 or 7 years old. Because the child can't identify before that. Also when parents identify symptoms like when the child squeezing the eyes while reading and keeping the book closer to the eyes etc. Only when there is any complaint... Also when the child is 4 years old, the child can't express its eye problem hence 6 or 7 years is ideal. (VT) Generally immediately after birth the child is taken for check-up with general physician. It would be good to have the eyes examined at the same time and after every 6 months till the age of 8 years to treat amblyopia. (VT) Immediately after birth eye check-up is necessary. Eyes are more important than hands and legs. After two months the mothers will identify any eye problems in the child. If any problem identified then they can go for eye check-up. (VT) At 6 years as it will be comfortable for vision test, the child will be able to understand and respond properly during the vision test. (VT) For all those who had consanguineous marriage the physician should inform about eye check for the baby immediately after birth. (VT) Yearly once eye check-up is sufficient for the child from the age of 3 onwards. (VT) Within one month from birth is necessary for all normal babies. Those who had critical delivery including Caesarean as soon as they are born is good. And afterwards once in 6 months is better. (VT)

		If we have to examine by birth every parents has to take their child to the eye hospital. In general, only they go to the hospital when there is any problem or when it is referred by the physician. The rural people have no awareness on eye check after birth. (VT) Children can't be express their eye problems hence if we screen the eyes of the child on yearly basis we can identify conditions early and treated... (VT) At birth especially on the premature children. We can check whether the retina is fully developed or not and we can do this by going to the hospital where the premature babies are present…(VT) Both kids and even adults can get check-up done every 6 months as refractive errors continue to change so it will be good to checked regularly every 6 months... (VT) At 8 years it is easy to do refraction and identify the vision problems so it's good to examine a child around 8 years. (VT) Children have high chances for amblyopia it's better to check their vision from birth. Once we identified refractive errors as per the doctor advice further screening could be done. (VT) After birth, we can examine from one month. Even if can't check the vision in young children, retina can be examined…(VT) We can start from 10 years for eye screening in children…(VT) Immediately after birth we can examine the eyes. For example in my home for a baby the doctor at the hospital checked the eyes with the help of torch light after 5 hours from birth so I think we can check the eyes from birth. (VT) After birth torch examination in the eyes is done by the doctors to check the eye movements in the eyes of the child. The doctors usually suggest the parents to take the child for eye check if there is any problems. It will be good to check the child eyes on yearly basis. As there are many possible tests to examine the eyes of the children, if they come for annual check-up we can examine how their vision are with the available tests…(VT) It's better to check up from birth as if there is any problem it will be possible to treat early... (VT) Along with cataract, retinoblastoma is another condition to be recognised early in children. It occurs mostly in below 5 years age children. It looks like a white cataract in the beginning and later look like cat eyes with shine on. If they are identified early they undergo complete eye ball removal or chemo treatment. It needs to be recognised early as they are life threatening. It will be good to raise awareness about this as well in the community when we get opportunity to work with the people…(VT)
Knowledge	Possible eye conditions can	Within one week or 15 days from birth some child will have redness / conjunctivitis and some may not have. But if we examine regularly, we may

	be identified in very young children	understand what type of cases are there and what more we can do to these children will be understood. (VT) Immediately after birth if we examine we can identify congenital cataract, glaucoma and even retinal problems. So it's better if they are examined immediately after birth. (VT) We can identify squint, retinoblastoma, cataract, glaucoma, micro cornea, bufophthalmos, big eye ball, corneal opacification etc. (VT)
Knowledge	Perception toward families' decision making dynamics	Mother, as she is responsible for looking after the child. She will be in a position to identify the problem but the decision to visit hospital is taken always by father. (VT) Mother informs the father and they both bring the child to the hospital. (VT) Whoever is more educated either the mother or father as they understand the importance of treatment. (VT) As there are more uneducated in villages, mother identifies and informs the father and them both take the child to hospital. But the decision is taken by the father on when to take the child to hospital. (VT) In villages, more than parents, grandparents' involvement is more in such decisions. Mostly the parents are working in agricultural fields and the children are under the care of grandparents. So they observe the children so closely in such case they take the decision. (VT) If both parents are educated either one of them take the decision and whoever is free will take the child to the hospital. In some cases both parents will take the child to the hospital. (VT) Always it's mothers' decision as the kids are closely monitored by the mother. Fathers always goes for work and they spend more time outside. Mother takes care of the child needs including food, medicine and all care… she the one who always identifies the problem… She also takes decision taking the child to the doctor. (VT) Even if she recognises the problem in the child she usually takes permission with her husband explaining the health condition of the child and takes the child to the hospital. They both will have decision about the child and take them to the hospital. (VT) In case of joint family whoever is the head of the family has to give permission to go to the hospital... (VT) Mother will be the first person to identify the problem or the next one would be grandmother. Even though the mother goes to work she will be able to identify any problem in the child…(VT)
Social influences	Gender issues at the community	The gender difference has come down due to change in generations. In 95% there is no difference but 5% of them still don't give same attention to the girls compared to boys. They still think the girl won't be helpful to the family, she will

go to another family after marriage and hence they show difference in the care. (VT)

Nowadays girls are given more care compared to the boys. More money is spent on boys these days. In my home, my sister is given the first priority compared to me. (VT)

There are differences in education as boys are sent to private school and girls are placed in government schools. They are not allowed to go out compared to boys. But when it comes to health care there is no difference and very few families show the difference. (VT)

Very few families show this indifference but mostly both are treated equally these days. (VT)

Both girl and boy is born to the parents and hence they need to treat both equally. In my family there is no difference all are treated equally including care, property etc. (VT)

Even in the society the situation has changed a lot. Nowadays girls are given more care compared to boys as the girls are looking after their parents well. After marriage the boys are not taking care of their parents. Recently I organised a camp, I brought 3 patients who have well settled boys but they didn't care for them. I only took them to the hospital and organised their treatment. (VT)

Haven't seen any such discrimination…It's equal nowadays in fact, girls gets more preference compared to boys these days. Because of the state government program (Bangara thalli) parents need not worry about dowry at the time of marriage… nowadays girls are treated better than boys…

Even there is no difference in the way the health care is accessed or provided to the children. (VT)

In general the situation is better in villages in terms of treating both boys and girls equally. But still there are places where they treat differently…For example in poor families the priority goes to the boys. Because they think boys will look after the family and hence they give more preference to boys' health and welfare. Girls will get married and go to other families but the boys will look after the parents so they treat boys better…In rich families both get equal treatment…(VT)

In my opinion in this state the preference is still goes for boys. For example if anyone gets married and they are expecting a first child the whole family will become happy if the first baby becomes a boy. They don't mind the next child to be girl or boy but they prefer boy as their first child. In case if the first child becomes a girl they will get into tension whether they will get a boy next or not…Even in my family, my wife had a c- section delivery for the first child and she told everyone when she heard that the child was a boy her whole pain

		disappeared out of happiness. Even women prefers to have male child as their first child…(VT) Whether it's poor or rich family, the father becomes very happy when a boy born in the family as his family generation will continue through his son. Treatment will be same for both genders but the feeling of having son is different and they feel proud to have a son…(VT) If the first two children are girls the family will go for further children till they get a boy…But if they had boy as first child then most of them will go for family planning after their second child irrespective of boy or girl as second one… (VT) There is no difference for seeking eye care between the genders. But there is some difference in seeking general health care in which girls gets delayed to treatment compared to boys…(CECW) Among educated families there is no difference but in some families where both parents are not educated they delay for both gender equally…(CECW) For mother both boy and girl are equal. If they understand the problem and the importance of treatment they treat both gender equally and if they didn't understand the problem they delay accessing services equally…(CECW) In case of female child if any surgery is advised they go for surgery as soon as possible thinking it might cause some problem in future during her marriage time. So for eye surgery girls gets quicker treatment whereas boys would get postponed or delayed by the parents…(CECW) If the girl becomes blind the parents think it will not be possible to get her married in future whereas the boys get married even they become blind, so they go for treatment early for girl child…(CECW)
Beliefs about capabilities	How do you convince the parents / carers	Earlier surgery used to take long time now it just takes 5 minutes so not to worry. If you don't get operated vision will reduce and there is a chance to become blind as well. (VT) Whoever accompanies the child either parents or grandparents we need to inform them about the surgery. If it is not operated, it will cause major problem. There are '**special doctors**' for operating the children... will motivate the parents and send them for surgery. (VT) Some old people will also not understand about cataract. Some usually argue when my grand dad didn't get cataract why you saying to my child? You saying just for the sake of money? But I always explain clearly saying in the current situation there is no difference between young and old. Anyone will get cataract. Children get cataract due to consanguineous marriage and if there are any genetical disorder in the family it can affect the child. It will reduce the vision and for this you need to meet the doctor at the higher centre. I will perform some check-up here and will refer you to the referral centre. (VT)

We need to clearly explain the good effects after surgery and the bad effects on the child's life if the surgery is not done on time... for the better life of the child the surgery is important and that need to be communicated clearly to them... (VT)

It's very important to check whether they understood what we communicating... in villages the way they speak is different and we need to ensure... are we speaking in the language that they will be able to understand... (VT)

We have to give many examples to make them understand the problem clearly... I feel parents are giving more importance to their child as they know the child has to live long and if there is any problem with vision his/ her whole life would be affected. (VT)

Many people come for check-up. If they are educated and when we explain about the child's eye problems and give them confidence that the vision will get improved after treatment if not everyone, some people go for further treatment…a few go for further consultation with different centres to check whether the diagnosis and advise given are correct. (VT)

We need to explain the details clearly about the problem. Go for eye check up and get it examined by the doctors and find out what is the condition and why it has occurred and whether it can be treatable or not etc. After knowing all the details… you can take a decision rather than saying that it occurs in the family and saying nothing can be done. If you go for treatment as advised by the doctor there is lot of scope for improvement in vision. But if we ignore and delay the treatment the vision will get further reduced and cause more problems…(CECW)

You need to go for check-up for your child's welfare and life. If you ignore and delay it the child's life will get affected…(CECW)

When we show some pamphlets with pictures they understand better, even if they can't read the text the pictures make them to understand what we communicate and make them think that even their problem may also be cured if they visit to the hospital…(CECW)

When we show pictures with problem and picture after surgery it gives clear understanding that the issue can be treated and they make their effort to visit to the hospital…(CECW)

Whatever we say some don't listen and neglect our advice. We need to have patience and repeatedly explain the need for surgery highlighting the importance of improved vision for their life…(CECW)

Also we need to explain that you parents are there to look after your child now but if his vision is not good who will look after him for the rest of child's life. So the early you seek treatment is better for gaining some vision back after surgery…(CECW)

		Even though they insult us we continue to visit their home… even if they scold us, we smile at them and leave. We go again and again till the family takes the child to the hospital….at one point even the family will start appreciating our patience in visiting them often…they will slowly start realising that we been visiting to their home for their child sake… to make them accept our work…. we need to work very hard…(CECW) They never listen at the first visit, we need to answer all their queries and explain everything in much more detail till they gain some confidence on us… it is important for us to communicate as if we are one of their family members… greeting them as sister / brother how are you? Such greetings makes them feel comfortable and it allows us to mingle with them…(CECW) It is very important get mingle with them to communicate easily…some when they come for screening and the child is identified with eye problems they thank us heart fully saying… if you didn't persuade my child to attend this screening we would not have identified his/ her eye problem… all these time we were thinking everything is normal in my child's eye…(CECW) We always address them by uncle, aunty, grandpa and grand ma etc. so that they listen to us as if one of their family member is talking to them. We need to explain patiently and ensure they understood clearly…they will listen to us…(CECW)
Emotions	Emotions	I won't explain about the surgery as they will get fear especially the child will get more fear and won't cooperate for surgery. So it's better to explain the parents when we refer the child for next level of service. (VT) Also I will explain the parents don't tease your child that he is not able to see properly... you are blind etc. some people scold the kids with such harsh words... because kids are so sensitive and it will hurt their feelings(VT).
Environmental context and resources	Perceived barriers	First is money problem, next journey problem ...a few people stay in remote rural areas for them long distance becomes a problem... Many doesn't know where exactly and which hospital to go... Those who live in rural area have no clues on how to go and locate the hospitals in the town... rural persons have problem in travelling to cities and economic reasons... (VT) They have fear about surgery also fear about failure for surgery (VT) Money problem, transport problem and if they are labourers they say, if we go we will lose our daily wage and it will become problem and hence they delay the surgery.... when it becomes too much problematic they will go to the hospital for surgery... only some people delay it and others will go as soon as referral is given. (VT) Negligence is also a problem meaning what will happen let's wait for some more time... (VT) Money problem and lack of awareness... not many are educated in rural areas

		and they not having clear idea about surgery and they have fear for surgery... (VT) Some people have negligence and some they take chances.... they may hope the vision will become normal after 10 days... and delay the surgery. Some may hesitate to travel so we need to ask whether there is any issue with attendees or they need any help from us to accompany them to the hospital. Or do they have any money problem… etc. we should ask them...it's not we insulting you... we are trying to understand if you have any problems so that we can try and help you. (VT) If they not going for next level for treatment it could be possible that they didn't understand our explanation about the condition of the child. Or the place we referred may be at longer distance or they may not be able to leave their work and take the child to the hospital… Parents in rural areas don't want to lose their daily wage and also they are not sure how much it would cost for the travel and treatment or they may not aware of the place they need to visit… Because of all these problems they may not go to the hospital for treatment even though they aware of the problem very well... (VT) When we explain about spectacles for refractive errors in children that the child's vision will improve with the spectacles they always think about the money. When they go for labour work they get around 300 rupees. If they had to take the child to the hospital they will lose their 300rs as wages and more over they had to spend money on spectacles as well. So parents most of the times decides it is ok for the child to manage with existing vision rather than spending so much money on spectacles and loss of wages etc.…. (VT) Children don't like to wear spectacles and moreover they break it often when the play either at school or outside. So parents sometimes thinks even if we spend so much money it goes waste as they don't like to wear or most of the times they break it. So many parents didn't like to spend money on spectacles. (VT) Instead of going to hospitals located in longer distance they try to show at somewhere near otherwise they just postpone it for a while…(VT) Parents don't have time to take the child to the hospital as they go for agricultural labour work. Also some have financial problems…(CECW)
Knowledge	Knowledge on post-operative follow up for childhood cataract	One week post op and again at 6 weeks afterwards once in 6 months if they come for check-up its better... because they are very young children they may get some other problems… They will have double vision and their activities will also be reduced. Also their confidence level will be low. (VT) If they come for follow up either at 3 or 6 months regularly even if they get other problems it can be identified early before it becomes bigger. (VT)

Every 6 months for lifelong the follow up has to happen…generally it's good to check vision every 6 months so even the child who had cataract surgery checks vision every 6 months it will be good I think... (VT)

Some cataracts are treatable. If the cataract has occurred from birth in most cases it comes along with amblyopia. In such cases vision will not improve just with surgery. They need patching after surgery and regular check-up and treatment on monthly basis. (VT)

It's is compulsory every once or two months to have the eyes examined. Parents may feel the vision has improved after surgery but we need to examine and inform how much vision is there in each eye as they are kids and they will not be able to inform about their vision. Either spectacles or patching need to be done so that they will gain some vision but we can't assure the vision will be completely normal in amblyopic eye…Along with surgery some more treatments are essential in children. (VT)

I'm not sure about how long the child need to come for follow up after surgery. But their vision on both eyes will be different they need to undergo patching and as per the doctor advice the treatment has to continue after the surgery. After that every 3 or 6 months once if they go for check-up it is good for the child... (VT)

I don't know how long the follow up will be required for a child after cataract surgery…(VT)

I think the follow up would be much longer as they are kids… and there is a chance for injury after surgery and we are not sure about the IOL implantation status so I think the follow up would be much longer... (VT)

After surgery within one week first follow up will be organised and after that every 3 months or every 6 months the follow up will be required depending on the child's eye condition. (VT)

After surgery the first follow up within one week and again at one month and afterwards every 3 or 6 months till they reach 20 years. The maximum growth will be achieved by 20 years and for any children eye problems the maximum follow up period is 20 years. (VT)

One month follow up is required I think, afterwards I'm not aware...(CECW)

I heard from someone after cataract surgery follow up is recommended at 40 days and a check after 10 years is recommended...(CECW)

I think For adults one month follow up is required but for children once a month for 6 months required after cataract surgery...(CECW)

Once a month for 6 months and after one year once to check their vision...(CECW)

		I feel they need to go for check-up lifelong. They shouldn't take it granted that the surgery is completed and they should come for regular follow- up once in 6 months for life long to check their vision...(CECW)
Knowledge	Knowledge on age at surgery for childhood cataract	If cataract occurs in a child it needs to be operated before 8 years because after 8 years the child will develop amblyopia. (VT) Surgery is based on age and the vision that the child has. In some cases it depends on the doctor who examines…some doctors advise it's not necessary to operate immediately ... ask them to wait for 3 or 6 months or come after one year...in such cases if the doctor advises to delay the surgery it's ok the child can wait for the operation. If the doctor didn't advice to wait all congenital cataracts need to be operated within one month from birth. (VT) There is no such time limit. I feel depending on their convenience if they can go early is better, that's my opinion. (VT) If its one month baby it will not cooperate. It may rub the eyes and the parents will feel fear to operate. I have seen very young kids getting operated but we need to explain the parents and get the child operated within one year. (VT) No idea… on what is the correct age for undergoing cataract surgery in children…(VT) At any age as and when it is recognised…(VT) We can do surgery on young children… I have seen a case who got operated at the age of 11 months when I was undergoing training at the tertiary hospital... (VT) We can do as soon as they are born within a week when they opened their eyes…in general after one month surgery can be done. (VT) After 21 days from birth the child can undergo surgery… as many in the village won't take their child outside for 21 days other than for emergency reasons…(VT) Don't know, may be at 15 years…(CECW) Even one year child can go for surgery. I have seen very young children undergone cataract surgery at tertiary centre…(CECW) Age has nothing to do it all depends upon the cataract. If the cataract is in operable stage, surgery can be done immediately and if the cataract is not in operable stage they can wait for some more time as per the advice of the doctor. It's our thinking but not very sure…(CECW) I have seen a case who was 7 years old with cataract and completed the surgery so I think 7 years old can undergo surgery. This is the first case I have seen in the field and he had both eyes cataract and they advised surgery for first eye and come to know about cataract surgery. Then I come to know that even 7 years old can undergo surgery…(CECW)

Environmental context and resources	Perception towards awareness creation	Awareness creation is must... Government or private organisations can do… TV ads can be good…highlighting cataract can occur in children and if not operated they can go blind and early surgery is important to treat the problem such ads can be given either by government or private organisation. (VT) All Social networking is a useful source. It's not possible to inform each and every one in person. So we can use social media. For example, advertisements in TVs. We can inform them every 6 months eye check-ups are important. People living in urban areas are aware of this, it will be useful for rural people more when they watch TV such ads will be more useful. They may start thinking maybe it's necessary to go for check-up. If not every time they may do it once in a while. This way we can reduce their problems. (VT) Nowadays most of the villagers' economic status is better and many are visiting private hospitals in towns and cities. If we can meet with those private doctors and introduce ourselves from eye hospital, especially at delivery homes and inform them to arrange for check-ups after delivery and ask them to inform the parents. Through this methods and through pamphlets and advertisement, if we do all these people go to hospital early. (VT) Everyone says different method, but I feel if we show videos to create awareness it will be much better. (VT) It costs lot of money for all media awareness. Instead we involve friends group at the village they can go and inform everyone at the village. Also we can contact panchayat and through them we can inform everyone. Many does this way...if we contact the panchayat they will do it at free of cost...community will think about president doing some good work for the community. Also through friends group we can inform the rural masses about eye care… Children eye care is our focus areas and hence we must create awareness in the community…If we create awareness on children eye problems the referral uptake will definitely increase... (VT) It is important to follow up with the family to check whether they went to the hospital for the treatment and them adhering all the advice given... we need to counsel one to one step wise in detail for them to understand the issues clearly… (VT) School screening has to be done. Also awareness talk or skit for 10 minutes on children eye diseases should be displayed in all local TVs. When parents see such ads on TVs they will associate with their child behaviour and take the child to the hospital…(VT) School screening is good but not all children go to school… So it is better to engage the community eye workers at the household level in every village. If we go door to door and discuss with the families who have young children and

		explain about the problems in a child, in a way that every parents understand … we can improve the referral rate by certain percent…(VT) Eye camps for children at the villages, school screening program and door to door screening at the villages will be useful. Most children goes to Anganwadi centres and if we create awareness among the mothers who visits Anganwadi centres they will recognise the problem early and take the child to the hospital…(CECW) Many parents in the villages do not recognise vision problems in children till they grow older. Only when the child unable to take whatever is given by the parents they start realising there is some problem in vision of their baby… so children eye screening is required… (CECW) At every village, village health nurse (VHN) maintains the list of new born babies for immunisation purpose. The hospital community workers can get the list from the nurse and visit door to door as per the list and we can recognise the problem early and refer it to the nearest vision centre to confirm the cases. Even if the worker has slight doubt she can refer the child to vision centre to confirm… (CECW) Care during pregnancy is important, especially they need to feed breast milk for the new-borns. If they feed artificial feed it will become a problem. School screening is important… also Anganwadi screening and follow up is must… (CECW) It's mainly due to lack of awareness about the problem and due to lack of education among the parents they delay the visit to the hospital for the children. … (CECW) There are a few examples in villages, Even kids realise that they can't see properly they fear to say that to the teachers thinking that they will beat them for complaining and also for same reasons they won't share it with the parents and have lost vision. … (CECW) As soon as the child informs if the parents take them to the nearby centres at least they can save the vision but if they delay it the problems becomes worst in the children. … (CECW) Similar to Anganwadi centres effort towards educating pregnant women about the care including nutritious food and immunisation etc. We need to create awareness about eye problems among children in schools. If we target the class 5 students and include the topic in their curriculum to educate them there will be changes in the future among the communities about eye problems… (CECW)
Beliefs about capabilities	Challenges at work	We explain very patiently to most of them but only 75% of them listens to us and 25%never listens to anything...they think who these young people advising to us...in such situation if we play video recordings...they will watch that and

		there is no need to explain. By looking at the video they will themselves come forward and ask for details if necessary. It will be easy as well as there won't be any necessity to explain individually. (VT) When we explain and give referral they confidently say they will go to the hospital. But later they say they will go to different hospital. Mostly they say that there will be a camp organised at our village and we will go through camp whenever it's organised...more than our words they give importance to their neighbours and others in the community... they listen to their advice more than our advice...some they listen patiently and the end they will say they need time to decide and if you ask them how much time required? They won't respond anything... (VT) When we refer we need to guide them properly... vision will become better but how much better will be able to suggest only after the surgery...but, if we say like this some may go but some don't go …if there is any doubt if their vision may or may not improve... (VT) Not many go to the hospital even after referral. They don't take it serious and they believe nothing will happen as the child grows older the problem will get resolve on its own… Thinking this way they won't go to the hospital for immediate check-up…(CECW) In the beginning the community always thinks that we going frequently to their home just for the job sake and they also think that we getting some commission or donations when everyone goes to the hospital etc. they also think that we unnecessarily referring them to the hospital… when we hear such comments it really hurts us and it will be a bigger challenge for us to gain their trust in the beginning…(CECW) They never listen to us in the beginning, at least we need to make three to four visits to make them listen to us. Even after number of visits if they don't listen then we usually identify another person who had received treatment from the hospital and request them to convince this person who is not willing to undergo treatment…(CECW) Too much time required for every process in the community…(CECW)
Social influences	Catalyst at the community	Nowadays children are close to their father as well. When dad spends more time with their child even he will be able to recognise the problem and show it to the mother and make a decision. (VT) Anganwadi nutrition centre workers they closely monitor the under 5 years children and they will be able to recognise the problem…(VT) Compared to all these health workers the person who spends more time with the children at home can recognise the eye problem easily based on the behaviour of the child and some symptoms like…not looking directly, when the eye lids are not closing properly etc.…So the person who spends more time

		with the child can recognise problems in children others can't recognise early. (VT) School teachers can identify based on how the child behaves in the school and inform the parents to take the child to the hospital. In some families kids are looked after by grandparents and sometimes they may not be able to recognise eye problems …also some parents don't care much about their children in such cases school teachers have major role in recognising the problem…(VT) Most fathers spends time outside for their work and mother spends more time with the children. She is able to compare her own child with other children and identify the difference quickly... (VT) Relatives, political leaders and some listen to the school teachers. If the teachers inform the parents saying that they have seen a few cases like this earlier and they say that the child is better after the treatment, some parents will listen to it…(CECW) In some families they don't even listen to their relatives in certain situation. For e.g. if the child has to go to a hostel facility for better education they won't listen to any one but if school teachers or church pastor speaks to them about the importance of education they will listen to them…(CECW) If we know that they particularly listen to some one in the family either it could be uncle or grandfather we need to discuss with them to convince the parents…(CECW)
Beliefs and consequences	Perception of the communities about squint	They consider squint as lucky especially in girl child. They don't go for treatment for squint…(CECW) Some believe squinted girl will get married to good husband in future…(CECW) Most of them feel it's lucky and they don't aware that there is a problem in the eyes and it could be treatable…(CECW) Some educated parents aware about this issue and they are taking the child with squint to various hospitals for seeking treatment…(CECW)